

LIBRARY SERVICES TO THE HANDICAPPED
IN THE PROVINCE OF ALBERTA:
A COMPARISON OF PRESENT SERVICE
AND FUTURE NEEDS

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FINAL REPORT
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AND FUTURE NEEDS

PREPARED FOR
ALBERTA LIBRARY SERVICES
TO THE HANDICAPPED

PREPARED BY
THE LEVY-COUGHLIN PARTNERSHIP
CALGARY AND TORONTO

JANUARY, 1983

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EXECUTIVE SUMMARY

1. GENERAL OBSERVATIONS RELATED TO LIBRARY SERVICE HANDICAPS

A "handicap," in the context of this study, is a situational disadvantage which a physically or intellectually disabled person experiences with respect to library services and library materials. It should be noted that a handicap is not an inevitable, direct result of a person's physical condition. For instance, a wheelchair-bound person is not handicapped when a public library is completely adapted for wheelchair use; similarly, a person with impaired vision is not handicapped when the material he or she wants is readily available in an alternative format appropriate to his or her abilities.

Library service handicaps can be grouped into two general categories: format related and environment related. In the first category, disadvantage results when a physical or cognitive disability prevents a person from using books, magazines, newspapers, and other standard printed materials. These handicaps of conventional formats are associated with impairments of vision, coordination, posture, strength, endurance, cognition, or comprehension. In the second category, an individual's disability places him or her at a disadvantage in using the services of a public library because the physical and/or interpersonal environments are not adapted to his or her abilities. These handicaps of the conventional library environment are most often associated with impairments of mobility, coordination, strength, endurance, or communication.

Because of two factors--1. the great variation in the way different individuals may be affected by a particular medical condition and 2. the high prevalence of multiple disabilities--library service handicaps are numerous and diverse. Consequently, the strategies for serving disabled persons must not be restricted to only one approach (e.g., provision of Talking Books), but rather must employ multiple approaches and be flexible enough to adapt to the unique needs of patrons.

2. THE EXTENT OF LIBRARY SERVICE HANDICAPS

Conventional Format Handicaps

Based on the best available data, we estimate that between 23,000 and 25,000 persons in Alberta are affected by handicaps of conventional formats (i.e., are unable or have great difficulty using standard printed materials). The prevalence by age group is estimated to be as follows:

Age Group	Prevalence Rate (Persons per 1,000)	% of All Print Limited Albertans
5-14	6	9.3%
15-44	5	26.7%
45-64	16	24.5%
65 and over	55	39.4%

Of the at least 23,000 Albertans who are print limited, about 55% have multiple limitations. The most common single limitation is caused by a visual impairment--34% of all print limited persons. The most common multiple limitation is both a vision impairment and another physical impairment (such as motor control, strength, etc.)--27% of all print limited persons.

The age structure of the Alberta print handicapped population and the high rate of multiple disabilities have important implications for the provision of services. Specifically, the greatest proportion of persons in need of alternative formats are elderly and have multiple disabilities. This fact implies that Talking Books could be as great a problem as print for the majority of the population in need because of difficulties in learning to use the playback machines and physically manipulating the tapes and playback machines.

The estimated proportion of the Alberta print limited population that has a cognitive or comprehension problem with conventional printed materials is 7%. Additionally, 28% of the print limited population has a cognitive or comprehension problem as a part of a multiple disability. Again, there is an important implication for service provision--there is a clear need for alternative format materials (e.g., Talking Books and large print) with high interest/low vocabulary content.

In general terms, print handicapped persons represent about 1.1% of all Albertans aged six and older. Using this estimate, it is possible to produce rough estimates of the print handicapped population for each community in the province. For example, Calgary is estimated to have a print limited population of 5,868; the estimate for Edmonton is 5,269.

It is important to note that all of the above-mentioned estimates are based on secondary analysis of available data. There have been no firsthand studies in Alberta to determine the extent of functional disabilities, much less to determine the prevalence of disabilities directly related to use of print. Hence the estimates are rough, order-of-magnitude figures at best. In particular, agency interviews and some literature indicate that the true number of persons with cognitive and comprehension limitations may be much greater than the figures produced here.

Handicaps of the Library Environment

It is even more difficult to estimate the prevalence of handicaps of the library environment than it is to estimate the prevalence of conventional format handicaps. The reason for the greater problem is that no studies were found which gathered reliable data on this issue.

Using more general data about disability, gathered recently in Ontario, we conservatively estimate that there are 53,000 Albertans whose primary disability would affect physical access and use of library facilities and services. This represents about 2.3% of the total provincial population. In addition, there are an unknown number of Albertans with a secondary or tertiary disability which could limit or prevent their use of libraries.

3. FINDINGS CONCERNING CURRENT LEVELS OF TALKING BOOKS REGISTRATIONS AND RECOMMENDATIONS FOR INCREASING THE NUMBER OF REGISTRANTS

According to the most recently available data, there are 2,215 Albertans registered for Talking Books, or about 9.6% of the print handicapped population. The proportion of print handicapped persons who are registered varies considerably across the province. For example, whereas Peace River shows about 71% registered, St. Albert shows only 1.3%. Registrations in the two major cities, Calgary and Edmonton, are 17% and 9.8% respectively.

Although one might expect a pattern of proportionately higher registrations at libraries which have delivery services (either staff or volunteer), no such pattern was found. However, one significant finding was that registrations tend to be proportionately lower in the smaller communities. This suggests a need to encourage libraries in the smaller communities to intensify their levels of outreach efforts.

About 82% of all Talking Books patrons are visually impaired. Print handicapped persons who are limited because of some other physical disability are under-represented among the registrants. This suggests a need to encourage libraries to intensify their level of outreach efforts to non-visually handicapped segments of the print limited population.

Thirty-five percent of all registrants are in institutions. In contrast, about 20% of the print handicapped population is estimated to reside in long term care institutions. This suggests a need to encourage libraries to intensify their level of outreach efforts to non-institutionalized segments of the print limited population.

procedures; and brochures which can be distributed to patients/clients/members.

As long as Talking Book titles represent only a fraction of the titles available in conventional formats, the print handicapped population will also be information handicapped, with its flow of information and its access to the cultural benefits of reading severely restricted. There is a need for a much wider selection of titles, especially in the following areas: high interest/low vocabulary; materials of short length (for persons with endurance and attention span problems); periodicals; reference; non-fiction, general interest (e.g., religion, current events, humour, nature, travel, do-it-yourself, history, and sports); and titles of local interest. Although the selection of titles is restricted by limited budgets and limited production, ALSH must recognize the paramount role which selection plays in the usefulness of Talking Books to potential patrons. ALSH--through its membership in library associations, its input to the federal government, and its contacts with publishers and Talking Books producers--should work to promote a vastly improved selection of Talking Books titles.

4. NEEDS AMONG THE PRINT HANDICAPPED POPULATION FOR SERVICES OTHER THAN TALKING BOOKS

Talking Books are not a "separate but equal" alternative to conventional materials available to the general public through public libraries, for the following reasons.

- Not all print handicapped persons are eligible for Talking Books under current interpretations of the eligibility criteria.
- Physical problems (e.g., lack of manual coordination, hearing problems) may interfere with or prevent use of Talking Books.
- Limited selection, especially in periodicals, reference materials, and specialized materials, means that Talking Books patrons have a much smaller range of titles available than do able-bodied readers.
- The relative slowness of listening as compared with reading, quality problems with readers, and the lack of a way to skim, flip through, or browse a Talking Book, all put patrons at a disadvantage.

Because of these several, significant shortcomings of Talking Books, it is important that public libraries develop compensatory services, to maximize the availability of library services to persons who are handicapped with respect to conventional formats.

In addition to educating key target groups about the Talking Books program and expanding the selection of Talking Books titles, there are four general areas which should be developed and promoted:

1. Collections of large print materials. It is important to note that data from a major U.S. study, substantiated by legally blind informants in Alberta, indicates that most print handicapped persons do use print. Only among the totally blind (different from legally blind) is print never used. Print limited persons struggle with print because they must--the desired material is often unavailable in alternative formats. Providing as many titles as possible in large print will go a long way to ease this struggle. Large print also has the advantages of being without eligibility restrictions; being more easily usable by learning disabled persons; requiring no special equipment to use; and providing a "normalized" reading experience. We recommend that ALSH thoroughly investigate all sources (domestic and international) of large print titles, if they have not already done so, and provide this information to public libraries in Alberta. Further, we suggest that ALSH make known to suppliers and to relevant organizations the urgent demand for additional large print titles in Alberta, in an effort to apply pressure to get more titles published. Additionally, we recommend that ALSH step up its efforts to promote exchange collections and demonstration blocks of large print volumes in smaller libraries.
2. Collections of high interest/low vocabulary materials. This is an extremely pressing need among segments of mentally retarded, learning disabled, elderly, and deaf populations. We recommend that ALSH investigate available titles on an ongoing basis and pass the information on to public libraries in Alberta; attempt to work for increased production of high interest/low vocabulary works; promote exchanges and demonstration blocks in the smaller libraries; and, if possible, provide small libraries with a set of "starter" volumes.
3. Technical aids. In order to enable print handicapped persons to use conventional and large print materials, public libraries should provide inexpensive technical devices, such as bookstands and magnifying lamps, for use in the library and on loan. More expensive and sophisticated devices can be set up in a library for patron use and patron education (e.g., to assist a blind person in making a purchase decision). However, the evidence in this study indicated that, in the short run, most patrons will not regularly use sophisticated, expensive equipment. We recommend that ALSH serve public libraries in the area of technical aids by researching and disseminating purchase information about available devices. It is important that

ALSH begin this task by finding out that information and experience already gained in the larger public libraries, some of which have devoted extensive effort to the task of researching aids and equipment. Another way in which ALSH can serve public libraries is to develop a demonstration collection of technical devices which can be loaned to libraries to aid them in their own purchase decisions. ALSH should also investigate the availability of adaptive devices to enable Talking Books use and forward the information to public libraries. In order to help libraries determine the value of such devices, it would be helpful if ALSH would purchase a limited number of each type of aid for try-outs by library patrons.

4. Programs of one-to-one service. Because some individuals will never be able to use any sort of print--even large print combined with magnifying devices--there is a need among print handicapped patrons for personal services. The specifics of the services required vary with the patron's disabilities and reading needs, but include reading aloud, changing Talking Books tapes in a playback machine, instruction in using the playback machines, and personal research (i.e., finding and reading reference material). In order to be affordable, such services must rely on volunteers. We recommend that ALSH educate librarians about how to run a successful volunteer program. Because some Alberta public libraries have already enjoyed considerable success with their volunteers, we recommend ALSH draw on those libraries as one source of information for preparing to educate other librarians who have not (or who have not tried).

5. **NEEDS AMONG DISABLED PERSONS WHO ARE HANDICAPPED WITH RESPECT TO THE PHYSICAL ENVIRONMENT OF PUBLIC LIBRARIES**

Physically disabled persons may face a series of barriers which prevent them from using a public library. An estimated 29,000 Albertans either cannot leave their own residence, or require special equipment or human assistance to exit from their own residence. An even larger number require special transportation services, especially in the winter months. Hence, there is a great need for homebound and institutional services, wherein the library delivers materials to the patron's residence. Several of the province's larger public libraries have developed such services for homebound patrons. We recommend that ALSH educate, encourage, and assist public libraries across the province to develop and maintain delivery programs for institutionalized and homebound persons. In this regard, the libraries will need ALSH's assistance in developing volunteer programs, because of the expense of staffing and equipping a delivery program.

Once inside the library, the disabled person may be faced with narrow aisles, books which are shelved too high or low, signs which cannot be read without near-perfect vision, catalogues which require manual dexterity to use, no way to carry books around, dust and mould in the atmosphere (critical to persons with respiratory ailments), and fluorescent lighting (a problem for some people with epilepsy or cerebral palsy). These are just a few of the scores of barriers which should, in the long run, be rectified. Realistically, however, the cost of necessary renovations may be prohibitive in the short run. In the meantime, we recommend that ALSH educate public librarians about the major barriers which disabled persons face in their libraries; and provide the libraries with guidelines which they can use when they do build or remodel. On pages 64-67 of this report there are 28 specific suggestions (many of which would not require significant expenditures to implement) which are examples of the kinds of information which ALSH can be using to promote awareness in public libraries.

6. NEEDS FOR REDUCING COMMUNICATION PROBLEMS WITH DISABLED PATRONS

The greatest challenge which public libraries face with respect to disabled persons is communicating the message that public libraries are for everyone--including those who are disabled. Our study found that, with the exception of a small group of elites, disabled persons are not accustomed to thinking that libraries are for them. Any attempts to develop special services to disabled persons must be accompanied by programs to promote such services to the disabled community. Without such promotion efforts, new services will be unused or heavily under-used.

We recommend that ALSH encourage and assist public libraries in developing and maintaining regular, formalized orientation and library use programs for disabled children. The details to be included in such programs are discussed on pages 69 and 70 of this report. We consider such programs to be the single most important expenditure of resources a library can make in any plan to develop equal access for disabled persons. In the process, the library will learn more and more about how it needs to adapt its services, while future generations of disabled persons will be willing and equipped to use those services.

Similarly, ALSH should encourage and assist libraries in developing orientation programs and materials to teach disabled adults and elderly persons to use the library. These programs should be developed in cooperation with local agencies and organizations.

It must be stressed that in the short term, new and innovative services, materials, and equipment will not be used by most people who could benefit by them. It is only in the long run, over a period of a decade or longer, that the level of use will begin to

About 73% of all registrants are aged 65 and older. This figure stands in sharp contrast to the estimate that 39% of print handicapped Albertans are in the 65-and-older age group. Hence there is a need to encourage libraries to intensify their level of outreach efforts to the non-elderly print handicapped population.

The largest unserved segment of the print handicapped population includes persons who are limited by cognitive and comprehension disabilities--i.e., mentally retarded and reading disabled populations. Current interpretations of the Talking Books eligibility criteria in Alberta exclude mentally retarded persons and make it difficult for reading disabled persons to qualify. The evidence gathered in this study indicates that Alberta is taking much too narrow an interpretation of eligibility. The intention of Talking Books is not to be exclusionary of people who are unable to use conventional formats because of an organically based impairment. There is an urgent need to either change the wording of the Talking Books eligibility criteria or to adopt and publicize a broader interpretation of them so that people who are print handicapped due to cognitive and comprehension disabilities no longer face major barriers to accessing the information available only in print formats or Talking Books.

A similar but less severe problem exists for persons who are visually handicapped, but not legally blind; and for persons with physical problems which make it extremely difficult, although not impossible, to use conventional print formats. Because the Talking Books eligibility criteria state that a registrant must be unable to use regular print, some signing authorities are apparently refusing to sign the registration form. We found cases, for instance, where ophthalmologists refused to sign for persons with diabetic retinopathy (and whose deteriorating vision prevents them from using regular print) until their vision reached legal blindness levels. Again, there is a need to either change the wording of the Talking Books eligibility criteria or to publicize a broad interpretation so that people with visual and other physical impairments do not face barriers to accessing the information available only in print formats or Talking Books.

In more general terms, there is still a common misconception that Talking Books are only for legally blind persons. To counteract this misconception, it is important to focus intense education and awareness efforts on target groups who can do the most to bring the Talking Books program to the attention of potential patrons. Repeated, direct mailings should go to public librarians, physicians, optometrists, senior citizens' organizations, and action groups and agencies serving disabled persons. These mailings should be detailed information packages containing the Talking Books eligibility requirements and procedures; "plain language" elaboration of the requirements, including the "gray areas" of eligibility; the reasons for restricted eligibility (i.e., the basis in copyright protection); the local librarian and ALSH staff person to contact when there is a need for clarification; a description of borrowing

approach the level of potential need. Thus, the installation of services, materials, and equipment is an investment in the future. If ALSH, a librarian, and/or a library board optimistically expect immediate, heavy use, they are bound to be disappointed. Even worse, they are likely to reduce or eliminate the innovation before giving it a reasonable chance to prove itself, assuming that the lack of use means it is not needed. An essential role of ALSH is to help educate the Alberta library community to cultivate reasonable expectations.

As a prerequisite to developing any special library services, librarians must be educated to understand the special needs of disabled persons. ALSH can assist the process of education by providing libraries with copies of this report and other informative materials, as well as supplying (and updating) a bibliography of materials for librarians. Also, ALSH should inform Alberta librarians of any conferences, workshops, continuing education courses, etc. which are coming up. ALSH can also promote education informally through its field staff and, more formally, through the development of materials and in-service training programs. However, any actual training materials and sessions should be developed by working with organizations of disabled persons. ALSH should also strongly encourage libraries to get staff training from local organizations of disabled persons. Most such organizations are willing and equipped to conduct workshops with professionals--such a library staff--to provide accurate information, promote sensitive attitudes, and give staff a chance to interact with disabled persons on a professional basis. The actual experience of being taught by a disabled person can be as valuable as the factual information that is presented.

In addition to the affective elements of communication, which could involve any disabled individual, the factual elements of communication may present a handicap to disabled persons with hearing impairments or communication disorder. We estimate that these may involve at least 23,000 Albertans. We recommend that ALSH educate librarians to recognize, understand, and deal with hearing and communication disorders; and encourage public libraries to equip themselves with TDD telephone facilities where local demand warrants the expense.

7. NEEDS FOR LIBRARY SERVICES IN LONG TERM CARE INSTITUTIONS

There are about 11,000 beds in Alberta long term care institutions (i.e., auxiliary hospitals and nursing homes). The majority of residents are elderly and are not regular readers. The larger institutions report a relatively larger proportion of regular readers --reflecting both the presence of in-house library services in the larger institutions and the services provided to them by major public libraries in the larger cities.

Vision problems are the greatest reported barrier to reading in the long term care institutions. Other major barriers are senility and

comprehension problems, and other physical problems (weakness, lack of manual dexterity, etc.).

A gross estimate of Talking Books eligibility in long term care institutions is about 20% of all residents--about 2,200 people. This figure was derived from the estimates provided by the responses to a sample survey of Alberta long term care institutions. Because of indications that institutional personnel do not understand the Talking Books eligibility criteria, the estimate of 2,200 people is open to serious question. However, it is clear that ALSH must extend its awareness efforts to long term care institutions, so that institutional personnel understand the Talking Books eligibility requirements.

The 23 responding institutions in our survey account for about one-quarter of all provincial long term care beds. Only 26% of the responding institutions reported that more than 5% of their residents are Talking Books users. Over one-quarter of the institutions reported no Talking Books users among their residents. Almost half of the institutions reported a need for more Talking Books services.

We recommend that ALSH encourage public libraries to develop strong ties with local institutions, to ensure that residents in need are supplied with Talking Books; and that those residents with complicating physical problems are given the human and technical assistance which they need to be able to listen to the Talking Books.

The successful programs of the Calgary and Edmonton Public Libraries, programs which rely heavily on volunteers, can serve as models for the smaller libraries in the province. It should be noted that success in an institution is partly dependent on obtaining the enthusiastic cooperation of the institution's activity director or volunteer coordinator (or a similarly designated staff member).

We also recommend that ALSH encourage local libraries to work with their local institutions to determine and help to fill the additional needs for library materials and services. According to our survey, the greatest needs in institutions are for (in rank order of importance): magnifiers and other technical devices; materials in languages other than English (especially German and Ukrainian); Talking Books; people to assist residents with their reading; and large print materials.

1. INTRODUCTION

1.1 PURPOSE

The purpose of this study, as defined in the original terms of reference (January, 1982) was, "to determine: a) the print handicapped population; b) those not currently being served by present Talking Books service; and c) the reading needs of, and scope of library service to, handicapped Albertans...." In the following sections, the current library service needs of disabled Albertans are documented and discussed in detail.

1.2 TERMINOLOGY

Conceptually, the report separates library service handicaps into two main categories. The first category, "handicaps of conventional formats," includes disadvantages which result when a physical or cognitive disability prevents a person from using books, magazines, newspapers, and other standard printed materials. Handicaps of conventional formats are sometimes referred to as "print handicaps" or "print limitations," and include the disadvantages which may result when a person has an impairment of vision, coordination, posture, strength, endurance, cognition, or comprehension. The second category is "handicaps of the library environment." These handicaps occur when an individual's disability places him or her at a disadvantage in using the services in the public library itself. For example, a person with lower body paralysis may be perfectly able to use conventional library materials, but be unable to get to the library, move about freely within the library, reach books off of shelves, and so forth. Similarly, a deaf person may be unable to use the telephone information services which libraries offer. Handicaps of the library environment are, in more general terms, the disadvantages which may result when a person has an impairment of mobility, coordination, strength, endurance, or communication.

It should be noted at the outset that a handicap is not an inevitable direct result of a person's physical condition. The word "handicap" refers to the disadvantage which a person experiences when conventional materials and services are inappropriate to his or her abilities. Thus, a person in a wheelchair is not handicapped when a public library is completely adapted for wheelchair use. Similarly, a deaf patron is not handicapped with respect to a library's telephone information services when the library is equipped with special TTY/TTD telephone facilities. A person with vision impairments is not handicapped when the material he or she wants is readily available in an alternative format appropriate to his or her abilities.

In other words, a handicap is not a physical characteristic of a person. A handicap is characteristic of situations which disabled persons experience.

1.3 REPORT CONTENTS AND ORGANIZATION

There were several sources of information for this report, including:

- statistics provided by Alberta Library Services to the Handicapped (ALSH);
- a literature review;
- telephone interviews with agencies and organizations representing and/or serving disabled persons in Alberta;
- discussion groups (called "focus groups") with disabled persons;
- interviews with directors and/or special services librarians at seven major Alberta public libraries; and
- a postal survey of a sample of long term care institutions in Alberta.

The data gathered from these sources has been integrated and is organized by the two categories of library service handicaps. Sections 1 through 6 address handicaps of conventional formats. Sections 7 and 8 deal with handicaps of the library environment. Section 9 addresses the special case of public library services to long term care institutions.

Extensive appendices follow the main body of the report. These appendices detail the study methods and instrumentation and summarize the findings of the agency interviews, the focus groups with disabled persons, and the interviews at the major public libraries.

2. THE NATURE OF HANDICAPS OF CONVENTIONAL FORMATS

2.1 PHYSICAL DISABILITIES AND CONVENTIONAL FORMATS

People experience handicaps with respect to conventional print formats for numerous reasons. The four major reasons* are described below.

1. Impairment of vision. Distorted vision, impairments of visual acuity, and reduced fields of vision can interfere with or prevent use of conventional print. The prevalence of total inability to use conventional print is probably lower than one might imagine. Even individuals who are "legally blind" may have some limited vision. In our consumer focus groups, blind individuals reported use of conventional print. A U.S. study (Berkowitz, et al., 1979) found that 22% of people who are legally blind use regular print more frequently than any other reading medium; 78% of vision impaired people (not legally blind) use regular print more frequently than other media. Technical aids (usually high intensity lighting, combined with high magnification) and/or working very close to the print allow it to be read. However, this is not to say that such use of print is "normal" use. The rate at which such reading can proceed is painstakingly slow, and fatigue and eyestrain result.
2. Impairment of motor control, range of motion, and/or body position. When hands and/or arms are absent, or manual dexterity is impaired, it may be impossible or extremely difficult to hold a book and turn pages. Immobility of the head and/or arms/hands can similarly prevent normal use of conventional materials. Finally, difficulty in maintaining a posture necessary for reading--because of spasticity, muscle weakness, spinal deformity, or extreme pain--may prohibit or inhibit the normal use of conventional materials.
3. Lack of physical strength and/or endurance. Extreme fatigue is an unexpectedly common barrier to use of conventional materials. The fatigue may be an indirect result of attempting to read in spite of one of the impairments mentioned above. Alternatively, fatigue may be more generalized, due to acute illness (e.g., cancer, kidney disease), or chronic cardio-vascular or pulmonary disease.

* Other reasons--not related to an organic impairment--include literacy and cultural disadvantage. These were defined as falling outside of the boundaries of this study.

Musculo-skeletal impairments can also be a cause, and in some cases the strength to hold a book or maintain a reading posture will be lacking.

4. Impairment of cognition and/or comprehension. Diseases of, damage to, or disorders of the central nervous system can result in generalized or specific disabilities in reading. In the cases of specific disabilities, the net effect may be an inability to mentally process the symbolic language of print. In the more generalized cases, intellectual ability may be impaired, thus preventing comprehension of conventional materials. The organic basis of some reading and intellectual deficits is a contentious and undecided issue within various scientific and academic disciplines. For certain individuals, an organic basis may be evident--e.g., brain or other central nervous system damage, a genetic abnormality such as Down's syndrome and Klinefelter's Syndrome, and some endocrinal abnormalities. Other organic bases are either hypothetical or cannot be empirically verified for particular individuals. In such cases, some professionals will assume or infer an organic basis, whereas other professionals will assume or infer a psychological or socio-psychological basis. In another vein, a profound hearing impairment or deafness prior to the acquisition of language can indirectly contribute to comprehension problems. Individuals so impaired have great difficulty in learning language syntax, and frequently have limited vocabularies. Thus, conventional materials may be incomprehensible to them.

2.2 THE PREVALENCE OF MULTIPLE DISABILITIES

It is not uncommon for a single individual to experience more than one of these four disabilities. There are at least two major reasons for the frequency of multiple disabilities. First, there is a strong correspondence between individual impairments and aging. A U.S. study found that 55 persons per 1,000 population above the age of 65 have a condition which limits their ability to use conventional print--in contrast with a general population rate of 12 persons per 1,000 population. Because aging persons are likely to experience more than one disease or disorder--e.g., cardio-vascular problems and arthritis--multiple disabilities are common among the population which is print limited. The second reason is the importance of the central nervous system to so many of the relevant disabilities. Damage or disease of the central nervous system often affects several functional abilities.

2.3 SPECIFIC PHYSICAL CONDITIONS WHICH MAY RESULT IN DISABILITIES WITH RESPECT TO CONVENTIONAL PRINT FORMATS

Table 2.1, which follows, details some of the major physical impairments which can contribute to limitations in the use of conventional print formats. The table is not intended to be exhaustive, but rather illustrative of some of the major relevant conditions and the way they can affect an individual's use of printed library materials.

TABLE 2.1

THE NATURE OF DISABILITIES WITH RESPECT TO
CONVENTIONAL PRINT FORMATS:
SUMMARY OF FINDINGS FROM LITERATURE REVIEW,
AGENCY INTERVIEWS, AND CONSUMER FOCUS GROUPS

1. BLINDNESS/VISUAL IMPAIRMENTS

(Associations with other disorders: diabetes, multiple sclerosis, aging; may result from brain damage, and thus be associated with mental retardation, learning disabilities, deafness, cerebral palsy, etc.)

A. Detailed Visual Tasks

- Major difficulties. Less frequently, total inability.
- Even legally blind individuals often can and do use conventional print, frequently with the use of high intensity lighting and magnifying aids. However, reading this way is a slow and painful process.

B. Motor Control, Range of Motion, Body Position

- Only if in association with another relevant disorder.

C. Strength, Endurance

- Endurance is a major problem due to eyestrain, and compounded by the extremely slow rate of reading.

D. Cognition/Comprehension

- Only if in association with another relevant disorder.

2. DEAFNESS/HEARING IMPAIRMENTS

(Associations with other disorders: when result of rubella or high fever or brain damage at birth, may be associated with blindness, cerebral palsy, mental retardation, etc.)

A. Detailed Visual Tasks

- Only if in association with another relevant disorder.

B. Motor Control, Range of Motion, Body Position

- Only if in association with another relevant disorder.

C. Strength, Endurance

- Only if in association with another relevant disorder.

D. Cognition/Comprehension

- Major problem, especially for adults who have been given limited education. Only the most recent generation of children are receiving a thorough education.
- Comprehension problems most severe among adults who have been deaf or profoundly hearing impaired since before the acquisition of language. "The average prelingually deafened person at age 12 has a vocabulary of 3,000 words, compared to a hearing person's 20,000." (Ritter, 1981)
- Agency representatives estimate that between 50% and 75% of all deaf and extremely hearing impaired adults either cannot read or have very low levels of reading ability. One representative suggested that the average reading level among deaf adults is Grade 4-5.

3. ELDERLY POPULATION (AGE 65 AND OLDER)

(NB: Aging is not a disability per se. Many older persons are perfectly healthy and able-bodied. However, aging is associated with increased prevalence of a number of diseases, disorders, and dysfunctions which can be disabling. Among the more frequent problems are vision disorders, hearing impairments, arthritis and related musculo-skeletal diseases, cardio-vascular disease, and Alzheimer's disease.)

A. Detailed Visual Tasks

- The CNIB (national) estimates that slightly more than half of Canada's blind population is age 65 or older. A survey in the U.S. (Berkowitz, et al., 1979) found that well over half of the population who has difficulty seeing to read is age 65 or older. Cataracts, a frequent source of vision impairment, are associated with aging.

B. Motor Control, Range of Motion, Body Position

- Range of motion and body position may be affected by arthritis or stroke, resulting in difficulty or inability to sit up, turn pages, and/or hold a book.

C. Strength, Endurance

- According to U.S. research (Berkowitz, et al., 1979), this is a much greater problem than one might imagine. Although the U.S. research does not break down the endurance problem by age, the implication is that aging is involved. According to that research, 36% of the print limited population is unable to read after a few minutes due to lack of endurance; another 10% have difficulty in this area.
- Strength and endurance problems are related to cardiovascular, musculo-skeletal, pulmonary, and acute diseases among the elderly population.

D. Cognition/Comprehension

- Alzheimer's disease, nutritional deficiencies, and the side-effects of medications can all contribute to comprehension problems among the elderly. However, except among institutionalized elderly persons, this does not appear to be a major barrier to reading regular print. It may be that the stereotype of the "senile" or "dottery" older person is overblown.

4. "MENTALLY RETARDED"*

(Associations with other disorders: when the result of brain damage, may occur in conjunction with other disorders caused by brain damage--e.g., cerebral palsy, vision and hearing disorders; when the result of genetic abnormality, may be accompanied by a wide variety of physical impairments, including rheumatic, endocrine, and pulmonary disorders; when the result of an endocrinal or nutritional imbalance or deficiency, can be accompanied by other physical disorders.)

A. Detailed Visual Tasks

- Only if in association with another relevant disorder.

B. Motor Control, Range of Motion, Body Position

- Although motor development delay may accompany mental retardation, the problems will not generally be severe enough to prevent the use of books.
- In conjunction with cerebral palsy, spasticity may prevent the physical use of books.

* "Mentally retarded" is sometimes seen as an objectionable label. We use the term because of a lack of any other common label that distinguishes between individuals with well below average intelligence and people who are either mentally ill or of average intelligence, but with specific disorders that interfere with reading abilities.

C. Strength, Endurance

- Only if in association with another relevant disorder.

D. Cognition/Comprehension

- Major difficulties. In some cases, total inability. Reading abilities may vary enormously with the education and stimulation that has been provided in childhood. I.Q.'s do not necessarily provide an adequate rule of thumb to reading abilities. It is being increasingly recognized that many mentally retarded individuals, previously viewed as not educable, can learn to read. However, the technology available to predict ultimate reading attainment is still at a primitive level. Because advances in education in this area are so recent, many mentally retarded adults cannot read, although they may have (had) the potential to learn to do so.
- Even when some level of reading is obtained, conventional library materials may be inappropriate. Mentally retarded adults find children's books to have inappropriate content, although at the correct reading level. The vocabulary of conventional adult materials may be beyond the reading and/or comprehension levels of the mentally retarded adult.

5. READING DISABILITIES

(NB: It is extremely important to note that the distinction between "mental retardation" and a reading disability is often artificial. The difference that is generally drawn is that learning or reading disabled persons have an I.Q. within the normal range, but have a specific inability or disability in one or more areas of perception and/or (more frequently) cognition. However, the same or similar causes may result in either a specific learning disability or a more generalized set of disabilities accompanied by lowered intelligence [i.e., "mental retardation"]).

A. Detailed Visual Tasks

- Some individuals may not "see" the written word, but there is a difference between the way a reading disabled person does not see and the way a blind or vision impaired person does not see. A blind person's dysfunction concerns the peripheral nervous system--e.g., the neurons outside of the brain. With a reading disabled person, the dysfunction is central--i.e., neurons within the brain are not working properly, because of damage or some disorder. Strictly speaking, the reading disabled person has no "vision" (perceptual) problems, but rather has "seeing" (cognitive) problems. The eyes

see the information, but the brain does not recognize or else distorts the information.

- Regardless of this neurological distinction, dyslexic individuals may have the inability or extreme difficulty in reading regular print. For some, larger, clearer print, with more space between letters and words, makes reading easier. Less material on each page is also a help for some persons.

B. Motor Control, Range of Motion, Body Position

- Reading disabled persons often have associated coordination problems. In fact, therapy to improve coordination often helps to improve the ability to read. However, coordination problems generally are not severe enough to affect the normal manipulations required for using books.

C. Strength, Endurance

- Not usually a problem.

D. Cognition/Comprehension

- Cognition is the crux of the problem for reading disabled persons--their brains do not properly process the symbolic information contained in print. As with mentally retarded individuals, there can be a huge difference between "potential" to read and actual reading achievement. In lieu of necessary "brain training"--i.e., the educational therapy to improve brain function--a reading disabled person may not achieve his or her potential reading level. Because in practical terms the necessary therapy and diagnostic tools are so new, adults with undiagnosed learning disabilities may be unable to read conventional print, although they have the theoretical ability to do so.

6. DIABETES

(NB: Although diabetes is a common disease, only in its rarer forms would it--in and of itself--result in disabilities with respect to conventional print. Additionally, complications of diabetes, also much less common than the disease itself, may result in disabilities.)

A. Detailed Visual Tasks

- Diabetic retinopathy, a vascular complication of diabetes, can result in blindness. The vision deterioration is gradually progressive rather than instant.

B. Motor Control, Range of Motion, Body Position

- The vascular complications of diabetes can ultimately result in amputation of the extremities, due to gangrene. Most usually, the feet are involved. In the less likely case of the hands, use of books would obviously be affected.

C. Strength, Endurance

- Diabetics are more prone to certain forms of heart disease than is the general population. Diabetics also tend to develop heart disease earlier in life than do non-diabetics. Hence, among elderly diabetics, severe weakness and limited endurance may be relatively common in interfering with the normal use of printed materials.

D. Cognition/Comprehension

- The arteriosclerosis which is more common in diabetics than in the general population most frequently affects the retina, the heart, and/or the extremities. Thus, the cognitive problems often attributed to arteriosclerosis (when it affects intracranial vessels) should not be expected to be particularly common among diabetics.

7. MULTIPLE SCLEROSIS (MS)

A. Detailed Visual Tasks

- Although blindness is rare, various vision problems--often transient--affect persons with MS. Some of the more common problems include nystagmus (rhythmic vertical or horizontal oscillation of the eyeballs), double vision, temporary paralysis of the ocular muscles, atrophy of the optic nerve, and changes in the field of vision. The vision problems often come and go, but at any given time, about 50% of people with MS will have difficulty in seeing to read (estimate by agency representatives).

B. Motor Control, Range of Motion, Body Position

- Spasticity and ataxia (irregular, tremulous, and ineffective motion) are common problems among individuals with MS. Like the vision problems, coordination problems come and go. Agency representatives disagreed on the prevalence of these symptoms at any one time among the MS population. The estimates of the number of people with MS unable to hold books and turn pages ranged from 20% to 70%.

C. Strength, Endurance

- Weak muscles and a tendency to fatigue upon minor exertion is also common among people with MS. The

agency representatives estimated that about half of the individuals with MS have strength/endurance problems at any given time.

D. Cognition/Comprehension

- Because MS is a disease of the central nervous system, cognitive functions can be affected. As with the other symptoms of MS, the problems come and go. Memory can be affected, and some MS patients will exhibit reading disability-like symptoms when the pertinent portions of the brain are involved.

8. CEREBRAL PALSY (CP)

(NB: The manifestations and severity of CP vary enormously among affected individuals. The condition results from central nervous system damage in utero, at birth, or in infancy. The extent of damage, as well as the part of the central nervous system that is affected [cortex, cerebellum, and/or basal ganglia] will determine the type and severity of the manifestations.)

A. Detailed Visual Tasks

- Between 20% and 40% of all individuals with CP will have vision problems that affect their ability to see to read conventional print (estimates by agency representatives).

B. Motor Control, Range of Motion, Body Position

- Spasticity is a frequent manifestation of CP. Agency representatives estimated that 40-50% of people with CP could not hold and manipulate books normally.

C. Strength, Endurance

- Strength and endurance is a less frequent problem (about 10%) than coordination problems among people with CP.

D. Cognition/Comprehension

- Depending on the type and extent of damage, individuals with CP may have mental retardation or learning disabilities. Unfortunately, estimates of proportions vary widely (from 70%, estimated in the 12th edition of the Merck Manual, to 5%, estimated by one of the agency representatives). All sources agree, however, that the number of mis-diagnoses in this area is high. Communication disorders have often made it difficult for people with CP to demonstrate their intelligence and--especially in the past--such individuals may have been labelled as slow or retarded early in life. A consequent lack of

of education can make the labels self-fulfilling prophecies. Nonetheless, there is no doubt that brain damage does impair intellectual functioning in some cases.

9. PARAPLEGIA, QUADRIPLÉGIA, HEMIPLEGIA

(NB: Although there are various causes, paraplegia and quadriplegia are usually the result of a traumatic spinal cord injury, often from a traffic or sporting accident. Hemiplegia is a common result of a stroke. Obviously, the types of disabilities experienced will vary depending on the quadrants of the body which are affected.)

A. Detailed Visual Tasks

- Not generally a problem.

B. Motor Control, Range of Motion, Body Position

- When only the lower body is involved, handling books in a normal fashion is not affected.
- When the entire upper body is affected, the individual is unable to hold books and turn pages.
- With hemiplegia, with only one side of the body affected, the individual may have difficulty, but not be unable, to handle books in ways necessary for reading.

C. Strength, Endurance

- Irrelevant in lieu of upper body coordination.

D. Cognition/Comprehension

- Not generally a problem.

10. MUSCULAR DYSTROPHY

A. Detailed Visual Tasks

- Not generally a problem.

B. Motor Control, Range of Motion, Body Position

- Major problem in later stages of the disease.

C. Strength, Endurance

- May be a problem in later stages of the disease.

D. Cognition/Comprehension

- Not generally a problem.

11. ARTHRITIS

A. Detailed Visual Tasks

- Not usually a problem.
- When an arthritic disease is associated with aging, vision impairment may also be a problem.

B. Motor Control, Range of Motion, Body Position

- Problems will be severe enough to limit reading in about 10% of cases (agency representative estimate).

C. Strength, Endurance

- In about 3% of cases, the problems will be severe enough to limit reading (agency representative estimate).

D. Cognition/Comprehension

- Not generally a problem.

12. BURN VICTIMS

(NB: Any materials provided to burn victims during the early stages would need to be sterilized.)

A. Detailed Visual Tasks

- Will be a problem in about 5% of cases (agency representative estimate).

B. Motor Control, Range of Motion, Body Position

- Position is a major problem in first year for victims of severe burns.
- Loss of limbs or loss of manual dexterity may result from severe burns.
- Handling books generally out of the question for the first several months because they would need to be sterilized.

C. Strength, Endurance

- Can be a major problem in early stages for severe burn victims.

D. Cognition/Comprehension

- Acute lack of concentration (due to pain and discomfort) is a major problem.

13. MISCELLANEOUS PHYSICAL IMPAIRMENTS

A. Detailed Visual Tasks

- Major groups and problems already mentioned.

B. Motor Control, Range of Motion, Body Position

- In addition to conditions already mentioned, may be problem for individuals with spinal deformation, acute spinal/back problems, congenital abnormalities involving hands and arms, amputated hands and/or arms, and individuals who have had polio.

C. Strength, Endurance

- In addition to conditions already mentioned, may be a problem for persons with chronic cardio-vascular disease, chronic pulmonary disease, and a small proportion of adults who have had polio.

D. Cognition/Comprehension

- Major groups and problems already mentioned.

3. THE EXTENT OF HANDICAPS OF CONVENTIONAL FORMATS

3.1 LIMITATIONS ON DEVELOPING ESTIMATES

There is no way to precisely determine the number and characteristics of the print handicapped population, short of formal survey research. A number of factors--but most especially, lack of recent, reliable, and pertinent empirical data--limit the accuracy of any estimates.

A more basic problem is a lack of a formal, operational definition of who is print handicapped and who is not. In other words, there needs to be an answer to the fundamental question, "How much difficulty must a person experience with conventional formats in order to be designated 'print handicapped'?" before any accurate survey research could be undertaken. As we have already noted, even legally blind individuals often use regular print. A person born without arms often develops incredible dexterity with his mouth and/or feet, such that it is possible to easily turn a book's pages. People with MS may have weeks, months, or years when vision is fine, interspersed with periods in which vision is impaired. People who have been profoundly deaf since birth are often functionally illiterate, but that is not a result of an inability to learn to read, but rather a difficulty with language (as a result of prelingual deafness) combined with a lack of satisfactory education. A person with Down's syndrome, born twenty years ago, may be totally unable to read although the unrecognized potential may have been there in childhood. Who is print handicapped? Where do you draw the line between "print handicapped" and "not print handicapped"? Until such questions are answered, any estimates--and even formal survey findings--will be subject to question.

Another problem is the fact that not all people with a particular medical condition will exhibit the same functional abilities and disabilities. MS and CP are good examples (refer back to Table 2.1 for details) of medical conditions which affect each person differently. Thus, even if highly reliable statistics were available on the numbers of people with such conditions, those statistics would not indicate who has disabilities which relate specifically to the use of print.

Another complicating factor is the differential accessibility of compensating technical aids. An individual with the financial resources to purchase sophisticated assistive devices* that ameliorate the difficulties involved in using print may no longer suffer a disadvantage. Should that person be considered "print handicapped"?

* Depending on the particular condition, such devices may or may not exist.

The presence of multiple disabling conditions poses another problem. For example, suppose we had accurate statistics on the number of Albertans who are blind, the number who have CP, and the number who are mentally retarded. If we added together the numbers, we would arrive at an overestimate, because there are an unknown number of people who have two or all three of these conditions.

In sum, we have precious few of the raw materials needed for a sound estimate of the number of Albertans who are handicapped with respect to library materials in conventional formats. Thus, the estimates in the following subsections should be considered very crude, albeit the best possible under difficult circumstances.

3.2 23,000 TO 25,000, THE "BEST" ESTIMATE: APPLYING THE RESULTS OF A RECENT U.S. SURVEY TO ALBERTA POPULATION DATA

Having attempted a number of approaches to estimating the Alberta print handicapped population, we consider the application of results of a U.S. study to be the best. The study (Berkowitz, et al., 1979) which involved a massive, nationwide survey in 1977, was undertaken by the American Foundation for the Blind for the National Library Service for the Blind and Physically Handicapped (NLS) of the Library of Congress. The purpose of the study was to determine the number and characteristics of the U.S. population eligible for the NLS. We consider it to be the "best" route to an Alberta estimate for the following reasons:

- No similar study--i.e., one which is large-scale, rigorous, and specific to print limitations--has been undertaken in Canada. Hence there is no solid, empirical Canadian data which we can use.
- No Alberta study has attempted to survey the disabled population, and thereby obtain reliable information about numbers and abilities.
- The only Canadian survey of the disabled population was carried out in Ontario (Ontario Ministry of Health, 1982), and it did not collect information specific to the abilities involved in reading.
- The NLS study, although it has a few weaknesses, is of superior conceptual and methodological quality.

In spite of the advantages, there are a number of shortcomings involved in transferring the data to Alberta. These include:

- Characteristics which differ between the two populations (e.g., age structure, proportion urban) may be relevant to the estimates, yet may not always be able to be corrected for.

- The precise, operational definitions used by the NLS study to determine if a person was "print limited" are not entirely clear, and may not be the definitions that would be preferred if one were designing a survey from scratch.
- Certain relevant medical conditions may have a different prevalence in Alberta than they do in the U.S., but the necessary data to adjust for such a factor is not in existence. For example, it was reported to us that the world's highest prevalence rate for MS is found in the Crowsnest Pass area, and that rates of muscular dystrophy (a set of genetically linked diseases) are extremely high in the Peace River area (information reported in agency survey).
- Similarly, the health care systems differ between the U.S. and Canada. This could affect the prevalence rates of various disabilities, but is another factor for which too little data is available for accurate adjustments.

Depending upon the particular result of the NLS study which we use, the Alberta estimate varies by about plus or minus 5%. A higher estimate is derived by taking the prevalence rate of 12 persons per 1,000 population, which the NLS determined as the regional prevalence rate for the U.S. mountain region. That region is directly south of Alberta, and includes the states of Montana, Idaho, Wyoming, Colorado, Utah, New Mexico, Arizona, and Nevada. The prevalence rate computed for the U.S. applies to the population who is aged six and older, but the most recently available Alberta statistics break down age groupings differently, such that we applied the prevalence rate to the Alberta population aged five and older. As of April 1, 1982, that population was 2,109,965. At a prevalence of 12 per 1,000, print limited population of Alberta would thus be 25,320.

However, this estimate assumes that Alberta's age structure is about the same as the age structure of the U.S. mountain states. Because the more southerly mountain states attract a large number of retirees, whereas Alberta has experienced sizable in-migration of young working and childbearing age people, that assumption is not true. Alberta has a proportionately larger concentration of people in the younger age groups. Berkowitz, *et al.* (1979, p. 135) found that "age is the most powerful predictor of prevalence rates," with the highest rates among the older age cohorts. Fortunately, that study provided prevalence rates by age group, allowing us to compute a more accurate estimate for Alberta.

Table 3.1 shows the estimated prevalence of print limitations in Alberta, using age specific rates from the NLS study (Berkowitz, *et al.*, v. 2, p. 37). There are slight problems with the estimate because of the unusual age groupings used in the NLS studies, but

the error is likely to be relatively minor. Taking age into account produces a smaller estimated print limited population, 23,062, because of Alberta's relatively young population. This figure translates into a prevalence rate of 11 persons per 1,000 population (about 1.1% of the Alberta population).

TABLE 3.1
ESTIMATED ALBERTA PRINT LIMITED, BY AGE

<u>Age Grouping in NLS Study</u>	<u>Prevalence Rate (Persons per 1,000)</u>	<u>Age Grouping in Available Alberta Data</u>	<u>Alberta Population in Age Group April 1, 1982</u>	<u>Estimate of Alberta Print Limited Population</u>
6-16	6	5-14	358,510	2,151
17-44	5	15-44	1,232,500	6,162
45-64	16	45-64	353,655	5,658
65 and over	55	65 and over	165,300	<u>9,091</u>
			TOTAL	<u><u>23,062</u></u>

Because it takes Alberta's age structure into account, the lower estimate of 23,062 is likely to be more accurate (within, of course, the constraints of the definitions of "print limited" made in the NLS study). Using this lower estimate, we can further apply the U.S. findings, to obtain rough estimates by type of disability. The NLS used a tripartite classification of print limitations: seeing, physical, and learning. These categories roughly correspond with the types of disabilities described previously (see Section 2.1) as follows:

"seeing" = impairment of vision

"physical" = impairment of motor control, range of motion, and/or body position; and lack of physical strength and/or endurance

"learning" = impairment of cognition and/or comprehension

Table 3.2 applies the findings from the NLS study (Berkowitz, et al., 1979, v. 2, p. 115) and applies them to Alberta, assuming 23,062 to be the Alberta total. The reader should note that additional error in these figures results from the fact that the proportions by disability type take into account neither age structures nor percentage of population urban/rural, both important factors which might alter the proportions for Alberta.

TABLE 3.2
ESTIMATED PRINT LIMITED POPULATION OF ALBERTA,
BY TYPE OF LIMITATION

<u>Type of Limitation</u>	<u>% of Print Limited Population (NLS Study)</u>	<u>Resulting Alberta Estimate</u>
<u>SINGLE</u>		
Seeing	34%	7,841
Learning	7%	1,614
Physical	5%	1,153
<u>MULTIPLE</u>		
Seeing plus physical	27%	6,627
Seeing plus physical plus learning	16%	3,690
Seeing plus learning	9%	2,076
Physical plus learning	<u>3%</u>	<u>692</u>
TOTALS (exceed actual totals due to rounding)	<u>101%</u>	<u>23,693</u>

It is apparent that multiple limitations are more common than single limitations. This has clear implications for service provision, especially in the case of persons with vision as well as physical problems. For such individuals, Talking Books could be as great a problem as print, because of difficulties in manipulating the tapes and the playback machines.

Another important point is that vision impairments, either singly or in combination with other limitations, are by far the most prevalent type of disability which limits use of conventional printed materials. However, the relative proportions may partially be artifacts of the NLS survey itself (the definitional issue again), if people with vision problems are more likely to recognize and report themselves as having trouble with print than are people with other impairments.*

It is possible to further use the U.S. data to make gross estimates of the print limited population for particular places in Alberta,

* Learning disabled adults are a case in point. The NLS study found that the vast majority of learning disabilities were reported among children and teens. Most learning disabled adults would not report themselves as such, simply because their conditions would not have been diagnosed.

simply by applying the prevalence rate of 11 persons per 1,000 (i.e., 1.1% of the population) to the population (age six and older) of a particular community. The reader is cautioned against taking the resulting estimates too literally, however. Even if the rate of 1.1% were not subject to limitations when applied to Alberta as a whole, it can be subject to extreme error when applied to individual communities. It is an average figure which can vary considerably from place to place.

The error may be especially severe in communities with unusual characteristics with respect to demographic or disability structure. For example, Fort McMurray has an unusually young population and an extremely mobile one. Therefore, it will have a smaller than average number of elderly print limited individuals and, quite likely, may have lower prevalence among younger age cohorts (because of an unlikelihood that disabled persons would have migrated to Fort McMurray and a likelihood that families with disabled newborns would move away). Another example is the Crowsnest Pass area. Within a 90 mile radius around the municipality of Crowsnest Pass is found an exceedingly high incidence of multiple sclerosis (4.2 persons per 1,000, the highest rate in the world according to a spokesperson for the local MS Society). In such a situation, the local print limited population would be larger than average.

In short, when applying general provincial rates to specific local communities there is always a risk of gross inaccuracy due to special local circumstances.

Bearing this in mind, we provide the following example, using Rocky Mountain House, to show how the rule of thumb can be applied.

TABLE 3.3

ESTIMATING THE PRINT LIMITED POPULATION
FOR A SINGLE COMMUNITY: ROCKY MOUNTAIN HOUSE

1981 Population (Census of Canada)	4,698
Subtract: Population age five and younger	<u>(470)*</u>
Result: Population age six and older	4,228
Estimate of print limited population: $4,228 \times .011 =$	47

* On average, the children aged five and younger constitute 10% of the provincial population. This figure of 10% has been used in our calculations. Obviously, there will be variations among communities.

Using the rule of thumb of 1.1% of the population aged six and older, we have calculated the estimated population which is handicapped

with respect to conventional print formats for Alberta's larger communities, and for general size ranges of smaller communities. This information is shown in Table 3.4.

One further note should be added regarding the use of this rule of thumb. Berkowitz, et al. (1979, v. 2, pp. 52-57) report that print handicaps are more prevalent in small and rural communities than they are in larger cities. This is true even after controlling for demographic age and sex structures. The geographic classification used by the U.S. Census and upon which this conclusion is based cannot be readily transferred to the Alberta situation. However, when using the rule of thumb for estimating prevalence in a particular community, one should bear in mind that:

- for communities smaller than 50,000 people, the rule of thumb is likely to produce an underestimate, unless the community is a functional suburb of a large city; and
- for communities larger than 50,000, the rule of thumb is likely to produce an overestimate.

TABLE 3.4

ESTIMATES OF THE PRINT LIMITED POPULATIONS
OF ALBERTA'S LARGER COMMUNITIES AND
FOR SIZE RANGES OF SMALLER COMMUNITIES

<u>Larger Communities</u>	<u>Estimate per Community</u>
Calgary	5,868
Edmonton	5,269
Lethbridge	535
County of Strathcona	511
Red Deer	459
Medicine Hat	400
St. Albert	317
Fort McMurray	307
County of Parkland	256
Grande Prairie	240
M.D. of Sturgeon	172
M.D. of Rockyview	172
County of Red Deer	135
County of Leduc	127
Camrose	124
Leduc	123
Ft. Saskatchewan	120
County of Grande Prairie	120
Improvement District No. 17	116
Spruce Grove	102
<u>Size Ranges of Smaller Communities*</u>	
6,000-10,000 (22 communities)	59-99
4,000-6,000 (40 communities)	40-59
2,000-4,000 (43 communities)	20-40
1,000-2,000 (49 communities)	10-20
Less than 1,000 (180 communities)	0-10

* 1981 Census of Canada, sizes of total population. Adjustments have been made for population under six years of age for computing estimates. The numbers in parentheses refer to the number of Alberta communities in that size range.

3.3 CORROBORATING AND CONFLICTING DATA

Throughout this section we have been layering caution upon caution with regard to the accuracy of the estimates that have been developed. This subsection will further serve to show the tenuousness of these estimates, by presenting data from other sources about populations which may be print handicapped.

A recent report published by the Canadian Department of Communications (Griffiths, 1981) drew on the same NLS study which we used in order

to estimate the print handicapped population in Alberta. The estimates in that study are lower than those presented here because the Department of Communications used 1976 Census of Canada data, whereas we have used 1981 Census of Canada data, as well as more recent updates published by the Alberta Bureau of Statistics. Because of the large growth in population in Alberta over the past six years, the Department of Communications estimates are far too low.

The "best" estimate calculated a population of 20,234 Albertans with vision limitations: 7,841 who have a vision limitation only, and an additional 12,393 who have a vision limitation as part of a multiple disability (see Table 3.2). These figures stand in sharp contrast to much lower figures provided by the provincial office of the CNIB (agency interview). The CNIB estimate was about 6,000 Albertans--3,000 of whom are legally blind and registered with the CNIB, and another 3,000 of whom are either legally blind and not registered, or vision impaired. In contrast, a recent survey in Ontario (Ontario Ministry of Health, 1982, and miscellaneous unpublished background studies) provides some data which is closer than the CNIB data to the "best estimate," but still lower. Using adjusted, age-specific data from that research and applying it to the Alberta population yields an estimate of 215,537 impaired (in any way) Albertans. Of this number, 3.79% (transferring the Ontario findings) would report "sight" as their primary disability. In other words, more than 8,100 impaired Albertans would list sight as their major functional disability. An unspecified number, in addition, would list sight as a secondary, tertiary, etc. disability.

Looking at the Ontario data in a different way produces a figure of 13,626 Albertans who are "handicapped" and would also list sight as a disability. This figure is produced using the following information. According to the Ontario survey, only 54.5% of the "impaired" population is actually "handicapped." This yields an estimate of 117,468 "handicapped" Albertans. In the Ontario survey, 11.6% of the "handicapped" population mentioned "sight" as a disability (11.6% of 117,468 = 13,626 Albertans). However, the decision rules that were used in the Ontario study to determine the proportion of the "impaired" population that is actually "handicapped" are subject to question and may have excluded a number of individuals with print limitations. Additionally, mentally handicapped persons were excluded from the study, so that people who are vision impaired as well as mentally handicapped are not counted. For these two reasons, the estimated total of 13,626 "visually handicapped" Albertans is likely to be an underestimate of the true figure for purposes of planning library services.

Although no firm conclusions can be drawn from this information, it is clear that other available data does not tend to corroborate the "best" estimate with regard to blindness and vision impairments. Instead, it tends to suggest that the figures from the "best" estimate are too high.

According to the "best" estimate, there are 12,162 Albertans with a physical disability that interferes with the use of conventional printed materials: 1,153 with the physical disability posing the only limitation, and 11,009 with a physical disability being one of multiple limitations. The data provided to us by agencies, unfortunately, was very poor and incomplete--not a reflection of the agencies' competence, but simply a reflection of the fact that reliable data on disabilities is generally lacking. Because of this, we turned to the recent Ontario data for additional evidence, supplementing it whenever possible with information gathered from the agency survey.

None of the Ontario data is organized in such a way that we can unambiguously estimate the number of Albertans with print limitations because of some physical problem. Table 3.5 illustrates the difficulty with the data. The table is based on a much larger list of medical conditions used in the Ontario study, and shows the proportion of the identified "handicapped" population which mentioned that condition first or at all. The numbers which result when we apply them to the Alberta population do not provide an estimate of Albertans who are limited with regard to print, for at least three reasons. First, not everyone with one of these medical conditions will experience a functional manifestation that limits his or her use of print. Second, other conditions not selected for this table could also affect the use of print (these conditions were too ambiguous with regard to print limitations to include in the table--e.g., "other respiratory"). Finally, although the Ontario data provides both the proportions of handicapped persons who mentioned a particular condition first and the proportion who mentioned it at all, it does not cross-tabulate the responses in a way that allows us to know how many people have multiple conditions which are on the list (e.g., how many people have MS only? how many have MS plus headaches? how many have MS plus arthritis? how many have all three? etc.). Thus, Table 3.5 can be thought of as estimating the minimum population at risk of having physical problems. The total estimate of 50,861 at risk is a minimum because it may exclude some relevant disorders and because it does not include multiple medical conditions.

Table 3.6 uses the minimum "at risk" population figure as a basis for calculating a minimum range of people who have a particular condition with manifestations that produce print limitations.* Where possible, we used the proportions estimated by agency representatives. In most cases, however, we were unable to obtain a reasonable estimate from an agency, and so we substituted an arbitrary, conservative estimate that 5% to 10% of handicapped persons with a particular medical condition would be physically print limited. The result of these calculations is a range of 3,000 to 9,000 Albertans with a primary medical condition which physically limits their use of regular print formats. The range is a minimum because

* Excluding vision, comprehension, and cognition limitations.

TABLE 3.5

ESTIMATES OF THE NUMBER OF "HANDICAPPED"* ALBERTANS
WITH SELECTED MEDICAL CONDITIONS THAT MIGHT LIMIT
THEIR PHYSICAL USE OF CONVENTIONAL PRINTED MATERIALS
(ASSUMING 117,468 "HANDICAPPED" ALBERTANS)

Medical Condition	% in Ontario Mentioning As "First" Problem	Estimated Number of Albertans	% in Ontario Mentioning Problem At All	Estimated Number of Albertans	(Agency Estimate)
Multiple Sclerosis	0.9	1,057	0.9	1,057	(3,000)
Cerebral Palsy	0.9	1,057	1.0	1,175	(1,700-3,000)
Parkinson's Disease	0.5	587	0.6	705	
Other Ataxias	0.5	587	0.6	705	
Headaches	0.5	587	1.3	1,527	
Spinal Cord Injury	1.5	1,762	2.2	2,584	(3,000-4,000)
Other Brain Damage	0.4	470	0.7	822	
Polio	1.1	1,292	1.1	1,292	
Other Neurological	0.1	117	0.6	705	
Cardiovascular	13.5	15,858	21.5	25,256	
Stroke	3.3	3,876	4.9	5,756	
Emphysema	1.8	2,114	2.8	3,289	
Arthritis (Rheumatoid and Degenerative)	12.2	14,331	25.0	29,367	(>300,000)
Muscular Dystrophy	0.6	705	0.7	822	(250)
Orthopaedic					
Disorder--Limbs	5.3	6,226	11.0	12,921	(1,000)
Burns	0.2	235	0.4	470	
TOTAL		50,861			
					N.A.

* Based on data from Ontario Ministry of Health, 1982, pp. 28-29. Note that persons who were--for purposes of the Ontario study--considered "impaired" but not "handicapped" were excluded from the study. The resulting figures may therefore be an underestimate when looking specifically at library service handicaps.

TABLE 3.6

ESTIMATES OF THE NUMBER OF "HANDICAPPED"* ALBERTANS
WITH PHYSICAL LIMITATIONS ON USE
OF CONVENTIONAL PRINTED MATERIALS, BY MEDICAL CONDITION
(ASSUMING 117,468 "HANDICAPPED" ALBERTANS)

Medical Condition	Estimated Number of Albertans**	Estimated Proportion Who Are Print- Limited ⁺	Estimated Number Who Are Print Limited
Multiple Sclerosis	1,057-3,000	20%-50%	211-1,500
Cerebral Palsy	1,057-3,000	40%-50%	211-1,500
Parkinson's Disease	587	5%-10%	29-59
Other Ataxias	587	5%-10%	29-59
Headaches	587	5%-10%	29-59
Spinal Cord Injury	1,762-4,000	5%-10%	88-400
Other Brain Damage	470	5%-10%	24-47
Polio	1,292	5%-10%	65-129
Other Neurological	117	5%-10%	6-12
Cardiovascular	15,858	5%-10%	793-1,586
Stroke	3,876	5%-10%	194-388
Emphysema	2,114	5%-10%	106-211
Arthritis (Rheumatoid and Degenerative)	14,331	3%-10%	430-1,433
Muscular Dystrophy	250-705	25%-50%	62-352
Orthopaedic			
Disorder--Limbs	6,226	5%-10%	311-623
Burns	235-1,000	60%-70%	141-700
TOTAL			2,729-9,058

* See footnote, Table 3.5.

** Taken from Table 3.5.

+ Estimates given in agency interviews are used where possible.
In lieu of an agency estimate, we have arbitrarily assumed 5%-10%.

it excludes persons with multiple medical conditions where the primary condition is not print limiting.

Table 3.7 presents a third application of the Ontario data to Alberta. The Ontario study estimated the proportion of the "handicapped" population with 21 types of "functional limitations"--i.e., the physiological or anatomical aspect affected by the medical condition. We have been conservative in selecting functional limitations from this list, including only limitations on use of arms and hands, and limitations posed by endurance and pain. Applying the data to Alberta yields a minimum estimate of 7,000 Albertans who have a physical limitation in using regular print. Again, this includes only primary functional limitations, while excluding persons whose secondary, tertiary, etc. condition poses a functional limitation.

TABLE 3.7

ESTIMATES OF THE NUMBER OF "HANDICAPPED"* ALBERTANS
WITH PHYSICAL LIMITATIONS ON USE
OF CONVENTIONAL PRINTED MATERIALS, BY FUNCTIONAL LIMITATION
(ASSUMING 117,468 "HANDICAPPED" ALBERTANS)

<u>Functional Limitation</u>	% in Ontario Mentioning the Limitation First (Primary)		Estimated Albertans Primary Limitation	
	At All		At All	
Hands	2.7%	7.5%	3,172	8,810
Arms	2.4%	7.5%	2,819	8,810
Endurance	0.5%	2.9%	587	3,407
Pain	0.3%	2.0%	352	2,349
TOTAL			6,930	N.A.

* See footnote, Table 3.5. Percentage of handicapped population with functional limitations taken from Ontario Ministry of Health, 1982, pp. 35 and 37.

The problems in comparing the data with the "best" estimate should be patently clear by now. However, the rough figures presented in Tables 3.5-3.7 seem to compare favorably with the "best" estimate that about 12,000 Albertans have physically-based print limitations. For example, applying the Ontario data to Alberta yields estimates that almost 9,000 Albertans have functional limitations on use of the hands, almost 3,500 have endurance problems, and more than 2,300 are afflicted with handicapping pain (Table 3.7). These figures

overlap (e.g., some people with arthritis may have both pain and limited manual dexterity), and therefore are not additive, but they would seem not to be in any great conflict with the "best" estimate.

There is very little data available on cognitive and comprehension problems related to reading. However, the data which was collected in agency interviews seems to indicate that the "best" estimate is low. According to the "best" estimate, about 8,000 Albertans are print limited due to a disorder which affects cognition and comprehension as a single limitation, and 6,458 in which cognition and comprehension is part of a multiple limitation. However, agencies which deal with learning disabilities estimate that about 15% of the population is affected and, of this number, about 75% suffer serious difficulties in reading. Applying these data to the Alberta population yields the estimate that almost 260,000 Albertans are reading disabled. Similarly, data from the U.S. indicate that approximately 3% of the total population is mentally retarded (American Library Association, 1980). Applied to Alberta, this would mean more than 69,000 people. A lower estimate of prevalence, 0.8%, was obtained from the agency interviews, but even this lower estimate means a population of more than 18,000 mentally retarded individuals in Alberta.

In summary, the accuracy of the "best" estimate of 23,000 to 25,000 print limited Albertans is difficult to assess. However, it appears as if the estimate may be high with respect to blindness and vision impairments; about right with respect to other physical impairments; and low with respect to impairments of cognition and comprehension.

4. THE TALKING BOOKS PROGRAM: COPYRIGHT, ELIGIBILITY CRITERIA, AND PROBLEMS

"Talking Books," literature recorded on tape, are an alternative to conventional print formats. They are one way to reduce the barriers preventing disabled persons from accessing information conventionally available from printed materials. However, Talking Books programs fall far short of the aim of equal access. There are at least four major reasons that Talking Books are not a panacea for people who are print limited.

First, the amount of material that can be covered per unit of time is much smaller when one must listen to it rather than read it. This is an inherent problem of the medium for which there is no conceivable solution. Second, physical disabilities among the print limited population may prevent or make difficult the use of Talking Books. For example, about one-quarter of the print limited population is hard of hearing (Berkowitz, *et al.*, 1979, v. 2, p. 127). Similarly, the same manual dexterity and muscular strength disorders which limit use of books can also prevent use of the Talking Books playback machines. Again, this is a problem of the Talking Books medium itself.

In contrast, the third and fourth reasons that Talking Books do not provide equal access are functions of the legislation and administration which govern their production and distribution. That is, they are systemic problems rather than problems of the medium itself, and thus are more amenable to solution. The third reason is Canadian copyright law, which until very recently limited Talking Books production; and the fourth is the set of rules (the eligibility criteria) which restrict who may borrow Talking Books and the way these rules are applied in Alberta. These two issues are the subject of this section.

4.1 CANADIAN COPYRIGHT AND TALKING BOOKS PRODUCTION

The number of titles available in the form of Talking Books is miniscule in comparison to the number of titles available in conventional formats.* This is in part due to cost and to limited production facilities, but the primary underlying reason for the small number of titles available has been a restrictive Canadian copyright law (which has been amended within the past year).

Talking Books production and distribution were apparently unintended victims of Section 19.1 of the Canadian Copyright Act. Although

* Approximately 2,600 titles are currently available in Talking Books format through ALSH.

the Section is intended to apply to recordings of musical works, it did not specifically exclude the recording of other copyright material until the recent amendment. Because the Section required "a compulsory licensing procedure which allows the use of any material electronically recorded by one party by another party, simply upon the payment of a modest fee" (Canadian Library Association, 1980, p. 7), copyright owners saw a possibility of losing control over their property, if Section 19.1 was applied to literary or dramatic works. As a result, producers and distributors of Talking Books had been repeatedly denied permission to reproduce, sell, or lend many copyrighted works in Talking Books format (Hébert, 1979).

Talking Books titles consequently represent only a fraction of the titles available to people without print limitations. Hence, the print handicapped population is also information handicapped, with its flow of information and its access to the cultural benefits of reading severely restricted.

Now that the copyright legislation has been amended to specifically exempt Talking Books from Section 19.1 (Hébert, personal communication, October 22, 1982), there is an opportunity to obtain a wider selection of materials. Available budgets and the size of the demand will still limit the new titles produced, but an important restriction has been lifted. Obtaining permission from the copyright holder should now be no more difficult than it is in the U.S. This would seem to open the door to purchasing Talking Books from U.S. suppliers, who offer a wider selection of titles than are available in Canada. The purchaser (e.g., ALSH or a public library) would need to provide the supplier with a letter of consent from the copyright holder, but there now seems to be no reason why the copyright holder would deny permission in Canada when it has already been granted in the U.S.

4.2 ELIGIBILITY FOR TALKING BOOKS

The literature and information which is available in Talking Books format is not available to a large part of the print handicapped population. Again, the problem has its source in the protection of copyright. Tapes are readily reproduced, and many non-disabled persons would use Talking Books if they could. Thus, copyright owners have lobbied for restrictions on Talking Books distribution, and understandably so. If Talking Books were too easily available, there is a chance that sales of printed works would decline, while the taped versions could easily be "bootlegged," thus diminishing royalties.

However, the spirit of the idea of recorded versions for disabled persons is being contravened by the letter of Talking Books eligibility criteria, as they are now written and interpreted in Alberta.*

There are four categories of eligibility for Talking Books. In Alberta (whose eligibility criteria are substantially the same as elsewhere in Canada**), "any patron who is unable to read regular print because of blindness, visual, physical or perceptual handicap is eligible for the service. The broad specifications for each category are as follows:

1. Blindness: Visual acuity of 20/200 or less in the better eye with correcting glasses, or, the widest diameter of visual field subtending an angular distance no greater than twenty degrees.
2. Visual Handicap: Inability to read standard printed material without special aids or devices other than regular glasses.
3. Physical Handicap: Inability to read or use standard printed material as a result of physical limitations, e.g., paralysis, missing arms or hands, extreme weakness.
4. Perceptual Handicap: A reading disability resulting from an organic dysfunction of sufficient severity as to prevent reading printed material in a normal manner."

* We make the assumption here that the intention of Talking Books is to give access to people who would otherwise be incapable of reading a work because of some physically based problem; and that Talking Books are not intended for use by people who, because of cultural or educational disadvantage, are illiterate in English--i.e., people who are capable of learning to read through the usual adult literacy programs provided in most communities. This assumption was confirmed in a telephone conversation on October 22, 1982 with Francoise Hébert, Director of Library Services, Canadian National Institute for the Blind, which is a major producer and supplier of Talking Books.

** The eligibility criteria are also substantially the same as those used by the U.S. Library of Congress National Library Service for the Blind and Physically Handicapped, which gives international compatibility of materials produced in one or the other country. However, the Canadian criteria is more liberal in who is considered to be a "competent authority," as will be discussed shortly (Hébert, personal communication, October 22, 1982).

In order to become a Talking Books patron, one needs certification from a "competent authority," including "any medical person such as doctor, ophthalmologist, optometrist, nurse, physiotherapist, or a case worker or an agent of a social service agency or association. This does not include teachers, except those special education consultants who have special psychological training."* Individuals who are registered as legally blind simply need to provide their CNIB registration number, in lieu of certification.

Depending on how the precise wording is interpreted, these criteria can exclude some individuals who are print handicapped. The problems arise from the wording of the criteria, and fall into two general areas: the use of the word "inability" and the category of "perceptual handicap."

As mentioned in Section 2.1 of this report, inability to read regular print is rare. Even "legally blind" individuals often are "able" to read regular print, albeit slowly and with great difficulty. The word "inability" is used in both the "visual handicap" and the "physical handicap" criteria, and its use may be excluding people who cannot use regular print because of great difficulty, although the signing authority cannot in good conscience certify that the person is "unable." This may sound like a petty point but, in fact, our interviews with agencies and our focus groups with disabled persons revealed that professionals run the gamut of interpretation from very liberal to extremely strict.

On one hand, we can relate the instance of a person with multiple sclerosis whose physician has certified him/her as eligible under the "visual handicap" criterion, but who regularly drives a car. At the other extreme are cases of individuals with diabetic retinopathy, whose deteriorating vision prevents them from using regular print, but whose ophthalmologists have refused to certify them for Talking Books until their vision reaches legal blindness levels. One agency even keeps an "under the table" listing of sympathetic ophthalmologists who will certify under the "visual handicap" criterion.

The point is this--as they are now written, the Talking Books eligibility criteria may seem to ask a competent authority to sign for something that he or she may not believe is completely true, i.e., that the applicant is unable to read and/or use standard printed material. If one knows a qualified authority who will take

* Personal communication with F. Hébert (October 22, 1982) highlighted the fact that in this regard, the Canadian criteria are more liberal than in the U.S., where only a medical authority can sign for a person in the "perceptual handicap" category. Miss Hébert also stressed the fact that this list is not comprehensive. Other professionals (e.g., a clinical audiologist) may also be considered to be "competent authority." However, Miss Hébert also pointed out that librarians are not considered to be competent signing authorities.

a liberal approach to the criteria, the wording may pose no problem. On the other hand, especially in small communities where the choice of specialists is small or nonexistent, disabled persons may not be able to obtain certification. This latitude in interpreting the criteria stems from inaccurate wording which is deserving of change. A simple solution might be to take the phrase "in a normal manner" from the "perceptual handicap" criterion, and insert it after the word "inability" in the "physical handicap" and "visual handicap" criteria. If this is not permitted, then it is important that ALSH communicate to the signing authorities that "in a normal manner" is intended or implied by the criteria.

The fourth criterion, "perceptual handicap," excludes a large proportion--perhaps a majority--of persons with limitations in cognition and comprehension. First of all, "perceptual handicap" is not a precise, accurate, or comprehensive term to refer to specific reading disabilities. The term "perception" refers to functions performed by the peripheral portions of the nervous system, i.e., sensory organs such as the eyes and ears. The problem in the case of a specific reading disability may not be so much with the eyes perceiving as it is with the brain cognizing the printed information. Cognition--the processing by the central nervous system of information perceived by the sensory organs--is often the crux of the problem in a reading disability. The brain simply does not make sense out of the information that the eyes see. "Perceptual" is a modifier that would be more accurately used in the context of blindness and visual disorders, where a sensory organ itself malfunctions. "Cognition" would be a more appropriate word to refer to the malfunctions in information processing and understanding functions of the central nervous system.

The wording of the "perceptual handicap" criterion puts the signing professionals in a potential bind. The criterion requires that the limitation stem from an "organic dysfunction." Very few medical personnel have the training to diagnose functional reading disabilities, although they may be able to determine their underlying organic basis. On the other hand, a specialist in education or psychology may be able to diagnose the nature and severity of the reading limitation, but is not qualified to determine the organic basis. This is one reason that it is difficult for a person with a reading disability to obtain certification. For the criterion to be followed to the letter would require the diagnostic services of both a medical specialist and an educational or psychological specialist.* Again, it is important that ALSH let professionals know that the intention of the criteria is not to be exclusionary. If, in the authority's professional opinion, the applicant is print limited because of a physical cause, then the spirit of the criteria is satisfied.

* Unless the applicant for Talking Books has access to a neuropsychologist with medical training--a rare possibility.

Another reason that certification may be difficult is that it may be impossible to determine an organic cause of the disability. Determining the organic dysfunction causing a reading disability is not often a simple matter. It may require extensive, sophisticated diagnostic procedures to examine the central nervous system, as well as other systems--such as endocrine function, which can biochemically affect central nervous system function. If the testing is thorough and appropriate, an organic dysfunction may be uncovered--most likely what is referred to as "minimal brain damage or dysfunction." When a lesion in the brain is found, a positive medical diagnosis is relatively simple. However, often the diagnosis is more difficult, because the problem may be caused by endocrine disorders, lead poisoning, radiation stress, malnutrition in the last trimester of pregnancy or in the first year of life, or a genetic disorder (Gaddes, 1980). To obtain the appropriate testing requires highly specialized medical professionals with access to highly sophisticated equipment. It also requires enormous persistence on the part of the Talking Books applicant.

When diagnostic procedures do not uncover an organic dysfunction, that does not mean that there is none. It may mean that the medical testing was of the wrong type or did not search deeply enough. Alternatively, it may mean that scientific knowledge has not yet advanced far enough to recognize the dysfunction. Finally, a third possibility is that there is no organic basis.

The inference which the professional draws in the absence of positive medical findings is in great measure a function of which current school of thought he or she subscribes to. Those who subscribe to the belief that reading disabilities generally have an organic basis will likely infer--and may be willing to certify--an organic dysfunction. Those who believe in a sociogenic or psychogenic theory of learning disabilities will infer a psychological cause.

In practical terms, if the criteria are interpreted very narrowly, the only Talking Books applicants likely to receive certification under the "perceptual handicap" rubric are either those with medically obvious brain damage (e.g., they have suffered a brain hemorrhage) or those who are able to find a sympathetic professional who is qualified to sign for certification and who will sign in spite of a lack of obvious medical evidence.

Certainly most adults with a reading disability are not likely to be able to meet the eligibility requirements. Learning disabilities have only been recently recognized, so that members of generations which have completed their schooling have not had access to the kind of educational testing that uncovers functional problems in reading. When they were children in school, they may have been seen as "slow" or "stupid" or "undisciplined," and there is not a high probability that such individuals will now seek and undergo extensive, stressful, sometimes expensive educational and medical diagnostic testing in order to gain Talking Books eligibility. Hence, they are unable to read, yet unable to qualify for the alternative to print.

We must reiterate here that Talking Books are not meant to be exclusionary or beyond the reach of individuals who have a physical problem which sharply limits their use of conventional print (Hébert, personal communication, October 22, 1982). The eligibility criteria are intended rather to protect copyright by preventing unnecessary use by people who can use regular print formats or by people who could use regular print formats if they enrolled in an English language literacy program. That is, people who are capable of learning to read normally but have not done so and/or people who are physically unrestricted in their use of conventional formats should not receive Talking Books.

Another major problem with the "perceptual handicap" criterion is that ALSH has been interpreting it to exclude mentally retarded individuals. The terms "reading disability" and "learning disability" in common parlance are meant to refer to individuals with I.Q.'s in the normal range.*

However, in terms of using conventional printed materials, many "mentally retarded" and "learning disabled" persons are in the same proverbial boat: Their central nervous systems cannot accurately process the information; they are denied the beneficial stimulation that comes from reading, as well as the important information found in print; and they may or may not be able to have an organic cause demonstrated. In fact, the distinction between "mental retardation" and a "reading disability" is "scientifically...an invalid idea" (Gaddes, 1980, p. 22). For instance, the same type of brain damage may cause one or the other manifestation.

There are certain cases in which mental retardation can be traced to an obvious organic source. For example, Down's syndrome and Klinefelter's syndrome are caused by genetic abnormalities. Brain damage at birth, when it causes cerebral palsy as well as mental retardation, is also an easily recognized organic basis. There seems to be no rational reason why individuals who are unable to read printed materials "in a normal manner" because of such organically based conditions should be denied Talking Books. Again, Miss Hébert noted that the CNIB does not believe that such mentally retarded individuals should be barred from using Talking Books (personal communication, October 22, 1982).

But, as with reading disabilities, an organic basis is not always demonstrable. Again, it may be inferred in the absence of positive medical findings, but so may a psycho-social cause. In practical terms, the eligibility criterion may inequitably exclude such

* The term "learning disability" was originated by S.A. Kirk in 1963 in an address to a group of parents and professionals. The next day, members of Kirk's audience organized the first chapter of the Association for Children with Learning Disabilities. Kirk specifically excluded from his definition children "who have generalized mental retardation" (Gaddes, 1980, pp. 23-24).

mentally retarded individuals, as it does learning disabled individuals.

There is yet another problem with the eligibility criterion for "perceptual handicaps." It may not be the disability per se which prevents reading in a normal manner. Rather, for some people it may be the combination of the disability and inappropriate/inadequate education. Current knowledge in special education allows many mentally retarded and learning disabled people to learn to read. These same people, had they been born a decade or more earlier, would either have been dubbed "unteachable" or would have been educated with less effective methods. Apparently, a key to some of the modern teaching methods is intensive stimulation of parts of the brain through a variety of physical and mental exercises. In simple terms, the goal is to maximize the potential of the working parts of the brain and to "train" certain parts of the brain to take over functions that would normally be accomplished by portions that are damaged.

A strict interpretation of the eligibility criterion would seem to exclude people who have (had) the potential to learn to read, but whose potential has not been developed through effective education. The criterion states that the organic dysfunction must be "of sufficient severity as to prevent reading printed material in a normal manner." Strictly speaking, it is often not that the organic dysfunction is so severe as it is that the teaching was (unavoidably) ineffective.*

The fact that intellectual stimulation can help to develop reading abilities among people who are print limited due to mental retardation or reading disabilities is the basis for a persuasive argument in favor of more liberal interpretation of the eligibility criteria. Use of Talking Books may provide therapeutic stimulation which actually helps to develop capacity to read, especially if the Talking Books are accompanied by the printed text. We were shown tangible evidence of this supposition in one of our focus groups attended by the parent of a mentally retarded adult. Her son is multiply handicapped, including a hearing impairment. When he was very young, his parents were told that he would never learn to read. However, for his amusement they were able to obtain recorded children's stories with accompanying picture-and-word printed texts. He could enjoy them only with the aid of amplifying earphones. Gradually his parents discovered that he was learning to read on his own. He is able to read as an adult, albeit at a simple level, in spite of professional predictions to the contrary, and his parents attribute the unexpected skill to the recorded stories.

The teaching value for adults who may have missed their chance for early stimulation is more questionable, but to supply them with

* We say "unavoidably" because the more effective techniques are recent discoveries.

Talking Books would harm no one if they are otherwise incapable of using conventional materials within the normal range of adult reading abilities.

However, the evidence concerning the spirit of Talking Books eligibility criteria indicates that ALSH is taking much too narrow an interpretation of the criteria. Mentally retarded persons should not be a priori excluded from the program and, more generally, ALSH should communicate to the professional groups involved that Talking Books are meant for everyone who is prevented from normally using conventional print formats because of a physically-based problem.

5. TALKING BOOKS SERVICE AND USE IN ALBERTA

5.1 TALKING BOOKS REGISTRATIONS

Alberta Library Services to the Handicapped (ALSH) provides Talking Books services through local and regional Alberta public libraries. Table 5.1 shows the current level of registrations by public library (or group of public libraries).

TABLE 5.1
TALKING BOOKS REGISTRATIONS
IN ALBERTA PUBLIC LIBRARIES

	<u># of Registrations</u>
Calgary	1,002
Edmonton	517
Deposit Libraries	
Lethbridge	38
Peace River	41
Red Deer	48
Grande Prairie	23
Medicine Hat	36
Regional Libraries	
Marigold	54
Parkland	115
Yellowhead	75
Others (74 public libraries)	<u>260</u>
Total	2,215

Source: Alberta Library Services to the Handicapped, as of September, 1982.

Hence, about 9.6% of the estimated 23,062 print limited population (see Table 3.1, previous) is registered for Talking Books. Outside of Edmonton and Calgary, the registrations are about 5.8% of the potential population.

The proportion of the print limited population which is registered varies geographically. For instance, in Calgary there are an estimated 5,868 people with print limitations (see Table 3.4, previous) and 1,002 registrations--a registration rate of 17%. Edmonton's

registration rate of 9.8% (517 registrations out of 5,269 print limited individuals) is closer to the provincial average. Some libraries are serving a much higher or much lower proportion of the print limited population. For example, Peace River has 41 registrations out of an estimated 58 print limited persons (71%); in contrast, St. Albert shows only 1.3% of the potential population registered (4 out of 317). Hence, the local variation in registration for Talking Books is considerable.

There are no standard benchmarks available to use to judge whether or not the utilization rates can be labelled "good" or "high." However, the extreme variations suggest that there are numerous public libraries which could be serving a larger proportion of the potential patrons.

According to breakdowns prepared by ALSH, the libraries are doing relatively better in registering visually handicapped persons and elderly persons than in registering other groups. The breakdown of registrations by type of limitation is shown in Table 5.2.

TABLE 5.2

TALKING BOOKS REGISTRATIONS
BY TYPE OF LIMITATION*

	<u>%</u>
Visual	82.0
Physical	13.7
Perceptual	3.0
Multiple	1.3

* Does not include Edmonton and Calgary. These libraries are not required to provide detailed breakdowns to ALSH.

These percentages are quite different from the estimates of the Alberta print limited population by type of limitation (see Table 3.2, previous). The most striking difference is in the multiple limitation category, which is estimated to include 55% of all print limited persons, but which includes only 1.3% of the registrations. Much of this discrepancy is likely to be an artifact of the Talking Books registration form. That is, signing authorities may be listing only the primary limitation rather than all limitations.

Table 5.3 shows the breakdown of registrations by age group. The striking feature here, when comparing the figures with estimates of the print limited population by age (see Table 3.1, previous) is the prevalence of registrations among persons ages 65 years and older. The estimated proportion of persons with print limitations in this

age group is 39.4%, whereas 72.7% of all registrations are among this elderly group. A possible reason for this bias is that 35% of all registrants are institutionalized.

TABLE 5.3

TALKING BOOKS REGISTRATIONS BY AGE GROUP*

	<u>%</u>
0-16 years	4.3
16-30 years	6.6
30-50 years	7.6
50-65 years	8.8
65 years and older	72.7

* Does not include Calgary and Edmonton.

5.2 TALKING BOOKS SERVICES AT THE MAJOR PUBLIC LIBRARIES

The way in which the Talking Books program is administered varies among libraries. A few of the larger public libraries have their own Talking Books and/or a deposit provided by ALSH. In most cases, however, the patron orders through the public library, which then receives the volume from ALSH. Some libraries also have playback machines for loan--either from ALSH or purchased by the library. Another area of variation is in the way that the patron gets the volume--some libraries deliver and others do not. Table 5.4 shows modes of delivery among the seven major public libraries surveyed for this study.

TABLE 5.4
MODE OF DELIVERY OF TALKING BOOKS
AT MAJOR PUBLIC LIBRARIES

	<u>% of Deliveries by Mode</u>			
	<u>Patron or Designate Must Pick Up</u>	<u>Volunteers Deliver</u>	<u>Staff Deliver</u>	<u>Other</u>
Library A	5%	95%	-	-
Library B	50-60%	30-40%	10%	-
Library C	100%	-	-	-
Library D	30%	3%	67%	-
Library E	100%	-	-	-
Library F	-	100%	-	-
Library G	100%	-	-	-

It is notable that, although one might expect proportionately smaller Talking Books registrations at libraries which require the patron (or a designate) to pick up the books, no such pattern was found.

5.3 INCREASING TALKING BOOKS REGISTRATION

The findings indicate that it is generally in the smaller communities where the proportionate Talking Books registrations are lowest. There is an obvious need for more outreach on the part of librarians in the smaller communities. The need for outreach is strongest for the non-institutionalized, non-elderly, and non-visually handicapped segments of the print limited population.

6. WAYS TO SERVE PEOPLE AFFECTED BY HANDICAPS OF CONVENTIONAL FORMATS

Providing Talking Books is only one way to serve the reading needs of people who have difficulty or are unable to use conventional print formats. As the previous sections have indicated, Talking Books do not presently serve most of the estimated 23,000 to 24,000 people in Alberta who have print limitations. Furthermore, for those who do use them, the Talking Books are not a "separate but equal" alternative to conventional materials available from public libraries. The selection is much poorer. Not only are there a relatively few titles available, but the titles which are available cover a much narrower range of subjects than the range of subjects available to able-bodied patrons. Periodicals, specialized materials, and reference materials are almost completely absent in Talking Books collections.*

In addition to these two major weaknesses (i.e., lack of current eligibility of all who need them and lack of selection), there are other aspects of Talking Books which prevent them from being a satisfactory substitute for users. These include aspects such as poor quality readers, the relative slowness of listening compared with reading, and the lack of a way to "skim" or "flip through" or "browse" Talking Books.

At the present time, there is no possible way to serve the print limited population so that they have equal access to the library materials available to the average public library patron. Although equal access should be a goal to aim for, it is not one that can currently be achieved. It will be possible to achieve only in the future, when affordable, sophisticated technical devices are available which allow disabled persons to use the conventional materials as easily as do able-bodied people, rather than having to rely on alternative media. Right now, such technical devices are relatively primitive, and often expensive. The Kurzweil Reading Machine is too expensive for most individuals to purchase for use in their own homes. When it is purchased for a library, it requires heavy staff attention--not only in training users (which takes between six and ten hours per person), but also in providing those users with one-to-one service in accessing the material they need. Although the New York Public Library Mid-Manhattan Branch estimates that the machine is down (out of service) about eight days per month (Weinberg, 1980), in Alberta, where service might not be as accessible as it is in New York City, down time could run much higher. In fact, the University of Calgary Library has purchased a Kurzweil Reading

* The CNIB has a magazine service, but it is presently limited to people registered as legally blind with that agency (Hébert, personal communication, October 22, 1982).

Machine, and blind participants in our focus groups reported that it is frequently out of service. Similarly, other technical devices such as automatic page turners are still fairly unreliable, often tearing or skipping pages (reported by focus group participants).

Right now, in the absence of the ideal technical devices that would allow disabled persons to use materials in conventional formats, there are three general ways that public libraries in Alberta can better meet the reading needs of the print limited population:

1. Improving the availability of materials;
2. Providing and educating about available technical aids; and
3. Providing programs of one-to-one service.

In the following subsections we discuss each of these general areas in detail.

6.1 IMPROVING THE AVAILABILITY OF MATERIALS

Clarifying the Talking Books Eligibility Criterion for "Visual Impairments"

As mentioned in Section 4.2, the criterion that visually impaired individuals be "unable" to read regular print is potentially confusing and unrealistic. It appears to be partly responsible for preventing vision impaired persons from qualifying for Talking Books in some cases, while in other instances, mildly impaired individuals are being certified as eligible. If the words "in a normal fashion" were added to the criterion, physicians might be more willing to certify visually impaired persons as eligible. For the same reason, the words "in a normal fashion" need to be added to the Talking Books registration form. Regardless of whether or not ALSH can change the wording, it should make sure that the registration form makes it clear that visually impaired individuals are eligible.

Clarifying the Talking Books Eligibility Criterion for "Physical Handicap"

For the same reasons, the words "in a normal fashion" need to be added to the "physical handicap" criterion, so that people who have great difficulty in turning pages, holding books, etc. are not excluded from the Talking Books program. If wording changes are not possible, the registration form should make the spirit of the requirement patently clear--that it is not meant to be exclusionary.

Clarifying the Talking Books Eligibility Criterion for "Perceptual Handicap"

There are multiple problems with the wording of this criterion, as discussed in detail in Section 4.2. We can find no reason why ALSH should not broaden its interpretation of this criterion to ensure that people who are print handicapped because of cognitive and comprehension impairments stemming from an organic problem or assumed organic problem are no longer barred from the Talking Books program.

Publicizing and Educating About the Talking Books Program

With the exception of the legally blind population, other potentially eligible individuals are often unaware of or confused about the availability of Talking Books. This issue came up repeatedly in the agency interviews and in the consumer focus groups.

Part of the reason is doubtless a preconception that Talking Books are only for blind persons. This preconception is not surprising in light of the fact that the CNIB did not extend the availability of Talking Books beyond the legally blind population until 1974 (Hébert, 1977).

Another reason is that the actual eligibility criteria have not been generally publicized and explained. As a result, even key individuals and groups such as ophthalmologists, action groups of disabled persons, and agencies serving particular disability groups are not aware of the categories of eligibility for the program. These individuals and groups are important sources of referral to the Talking Books program, and they need to be educated about it.

We recommend publicity and education about Talking Books' availability by means of direct mail contact with key individuals and groups. General public advertising campaigns are frequently expensive and ineffective. Radio and television public service announcements are broadcast at odd hours when the audience is small, and newspaper ads can be buried in obscure locations. For these reasons, we suggest that educational and awareness efforts be focused on specific target groups who can be easily identified and reached.

The information that needs to be disseminated includes:

- the verbatim eligibility requirements and procedures for registration;
- "plain language" elaboration of the requirements, including examples of cases of eligibility and making the spirit of the requirements clear;
- frank explanation of the "gray areas" of eligibility, and the fact that signing authorities

do vary in whom they will certify as eligible;

- the reason that eligibility is restrictive (the basis in copyright protection);
- the name, address, and phone number of the local librarian and the ALSH staff who can be contacted when there are questions or need for clarification;
- a description of the number and types of titles available in Talking Books format;
- a description of the procedures for borrowing Talking Books; and
- brochures which can be distributed to patients/clients/members.

Examples of individuals and groups who should receive the information are:

- public librarians (so that they are aware of the information that is going out to the public);
- physicians (a mailing list can be obtained from the Alberta College of Physicians and Surgeons);
- optometrists;
- senior citizens' organizations; and
- action groups and agencies serving disabled persons (a list can be prepared by the Alberta Social Resources Inventory).

Several of the major public libraries reported to us that direct mailings to ophthalmologists and agency caseworkers have been an effective way to promote their Talking Books program. On the other hand, librarians in two communities got a poor response to a mailing campaign. A widespread mailing to potential referral sources is a way to attempt to make sure the eligible population is informed about the service, but it is important to recognize that not all recipients will read and use the information. Periodic repeats and updates are necessary because of staff turnover within agencies, new agencies and physicians starting up, and the simple fact that such materials often get misplaced.

Improving the Selection of Talking Books Titles

In Section 4.1 we pointed out the problem of limited Talking Books titles. It is important to reiterate, however, that Talking Books are not presently an adequate alternative to regular print because of the limited selection. Additionally, two particular areas of need are noteworthy: high interest/low vocabulary titles are especially needed because of the high proportion of elderly among the print limited population, many of whom are experiencing comprehension, concentration, and attention span problems (Berkowitz, et al., 1979, v. 2 and 4: agency interviews; institutional survey). High interest/low vocabulary works are also important to reading disabled individuals who have multiple language disorders; to mentally retarded persons; and to older physically and visually disabled individuals who were denied an adequate education because of their disability. Non-fiction is a second important area. The majority of Talking Books titles are fiction, but the U.S. survey of people with print handicaps found a greater interest in non-fiction (Berkowitz, et al., v. 2, pp. 322-327). Table 6.1, below, presents those findings.

TABLE 6.1
TOP TEN SUBJECT INTERESTS OF THE
U.S. PRINT LIMITED POPULATION

<u>Subject</u>	<u>Fiction (F) or Non-Fiction (NF)</u>	<u>% of Population Expressing Interest</u>
Religion	NF	70%
Short Stories	F	68%
Current Events	NF	64%
Humour	F	62%
Nature	NF	61%
Travel	NF	55%
Do It Yourself	NF	50%
History	NF	45%
Mysteries/Thrillers	F	43%
Sports	NF	41%

We should note here that there is also a need for more challenging material, which might be partially satisfied by a larger selection of non-fiction. Blind and visually handicapped participants in our focus groups were particularly critical of what one person called "the titles that seem to appeal to the Harlequin Romance crowd."

We received several suggestions from librarians and interviewees that locally written materials be recorded by ALSH, using volunteer readers, in Talking Books format. These informants noted that the copyright owners of such materials would be apt to give permission and that the materials would be of special interest to elderly Talking Books users.

Expanding Large Print Collections

Expanded collections of large print titles would be of tremendous value to parts of the print limited population. The majority of the print handicapped population do use print. The NLS study in the U.S. (Berkowitz, et al., 1979) found that only about 33% of people who are print limited do not use either regular print, large print, or both. Only among totally (not necessarily legally) blind persons (a small proportion of the print limited population) is print never used. In our focus groups we found a strong preference for printed media. The preference did not seem so much born of a particular fondness of using print. On the contrary, using print--especially regular print--is a painful struggle. However, the limited availability of material in alternative formats forces people to use regular print in order to get the information they need or to read the material they like. Also, a dislike of the quality of Talking Books readers and the difficulty in skipping about within a book also turns people away from Talking Books.

Print limited people turn to print because they must. Even legally blind persons, often using technical aids, struggle with regular print. If a wider variety of large print titles were available, the struggle would be somewhat eased. Improved large print collections would benefit blind, vision impaired, and learning disabled persons, but not those whose sole problem is in manipulating books.

Besides being easier to see than regular print, large print has advantages over Talking Books. There is no need to burden either the patron or the library with certification for eligibility. For people who have been readers all their lives and who are experiencing gradual vision deterioration, large print represents a less drastic adjustment than the switch to Talking Books. An additional advantage is that some people with reading disabilities can read more easily when print is large and well spaced. No special equipment is essential to the use of large print, whereas Talking Books require playback machines. Ordinary repair procedures can be carried out at the local library when a large print book is damaged, whereas damaged tapes are not so easily repaired. One of the most important advantages of large print is that it is a "normalized" reading experience, in contrast with the unusual aspects of listening to a Talking Book or being read to by another person. Disabled persons and their organizations have been becoming increasingly concerned with the issue of normalization in the activities of daily living, a concern which is well met by large print.

The need for expanded collections of large print materials cannot be overemphasized. It came up repeatedly in our focus groups, agency interviews, interviews with librarians, and institutional survey. The librarians especially emphasized the heavy use their large print collections receive. One told us:

We have about 4,000 titles in large print--just about all that are available. We just can't meet the demand. The circulation is about 22,000 volumes per year, and that doesn't include circulation at our branches, where we send collections.

Another librarian called the large print collection "more important than Talking Books," with a much larger readership and higher quality than Talking Books.

Unfortunately, there is a major stumbling block to meeting the demand for large print, and that is the limited availability of titles. The librarian just quoted told us that the library receives about two dozen requests per month for large print titles which are unavailable. One librarian pointed to a need for large print titles in paperback for the frail elderly. Two mentioned the dearth of large print titles for children and young adults. A librarian in one of Alberta's smaller communities phoned us recently about this problem. She had heard about our study from an agency official whom we had interviewed in her town, and kindly phoned us to pass along the results of some research she had been doing for two teen-aged patrons who need large print. She reports that there are only 38 young adult titles in Canada, and 12 of these are out of print. She has had some limited success in ordering a few large print young adult titles from England.

It was beyond the terms of reference for this study to investigate the availability of large print titles. However, we recommend that ALSH thoroughly investigate all sources (domestic and international) of large print titles, if they have not already done so, and provide this information to public libraries in Alberta. Further, we suggest that ALSH make known to suppliers and to relevant organizations the urgent demand for additional large print titles in Alberta, in an effort to apply pressure to get more titles published.

Additionally, we recommend that ALSH step up its efforts to promote exchange collections and demonstration blocks of large print volumes in smaller libraries. Only the two very largest public library systems in the province, Edmonton and Calgary, have "complete" collections--complete in the sense that they have acquired the titles which are readily available. The smaller the community, the more the support that will be needed in developing and bolstering large print collections, because very small communities are so financially limited in the number of volumes that they can acquire.

Developing High Interest/Low Vocabulary Materials

There is also an urgent need for more high interest/low vocabulary materials, in regular print as well as in large print and Talking Books. High interest/low vocabulary works obviously serve the mentally retarded and learning disabled populations. However, they have broader utility because much of the older disabled population which has been disabled since childhood has received inferior education. Elderly persons who have become disabled in old age also may have received a small amount of schooling, particularly if they grew up in a non-English speaking country. Furthermore, the frail elderly may possess diminished powers of comprehension and concentration.

Another disabled group which would benefit from high interest/low vocabulary materials is the deaf population. In the agency interviews, respondents repeatedly stressed that the level of literacy among deaf persons is extremely low. The deaf population, more than other disabled groups, has suffered from a lack of adequate education in Alberta until the past decade or so. This lack, combined with the difficulty that deaf persons experience in acquiring language, has resulted in a literacy level which one agency representative estimated to average at a Grade 4 or 5 level among deaf adults.

Of course, high interest/low vocabulary works also are useful to non-disabled segments of the general population, particularly immigrants just learning the language and people who have been educationally deprived.

Among our focus groups, individuals representing the deaf, mentally retarded, and learning disabled populations spoke most vehemently about the need for high interest/low vocabulary materials. The same groups' agency representatives also stressed this need. All noted that teenagers and adults tend to stop reading because children's books, which they can read, are totally inappropriate. They requested titles in two general areas: recreational and how-to's. Representatives of mentally handicapped adults pointed out that normal avenues for recreation are often closed for the group, that mentally handicapped adults can find evenings and weekends to be very lonely times. The opportunity to visit the library and borrow books for recreational reading, the informants stressed, could help to fill the void with some pleasure. The sorts of areas suggested for recreational reading included sports, humour, and books with a large pictorial content. One suggestion for an inexpensive way to provide interesting material for people of low intelligence was catalogues, which have pictures and information of interest to adults. One of the librarians at a major library mentioned that the library has ordered "photo novels"--i.e., fiction that uses pictures to tell the story. The how-to need appears to be extremely important among all groups with cognitive and comprehension problems. Information on cooking, finances, etc., written at a simple

reading level, would help to increase an individual's independence as an adult.

Librarians at the major libraries echoed the sentiments of the focus groups and agency representatives. Five of the seven librarians interviewed spoke either of a large unmet need for high interest/low vocabulary materials to serve elderly, deaf, learning disabled, and mentally handicapped populations, or of the heavy use which high interest/low vocabulary materials now receive.

We noted two opposing views about how high interest/low vocabulary materials should be shelved. One view is that the collections should be "hidden," so as to prevent embarrassing the patrons who use the materials. The opposite opinion is that the materials should be well labelled so that the patrons who need them can easily find them. We tend to agree with the latter view, for the simple reasons that: (1) people with cognitive and comprehension problems will have difficulty finding the materials if they are not easy to find, and (2) having to ask where the materials are may be equally or more embarrassing than browsing the collection. We suggest that the high interest/low vocabulary works be shelved in a very prominent location in the library with a sign carrying an easily understandable, non-threatening sign, such as "Easy Reading" or "Easy to Read." The current jargon used by librarians--"literacy collection" or "high interest/low vocabulary"--is not known or understood by the general public, much less by people with comprehension difficulties.

The ways in which ALSH can help promote such materials in public libraries involve the same sorts of activities involved in promoting large print collections: investigating the titles that are available and passing the information along to librarians; attempting to work for increased production of high interest/low vocabulary works; promoting exchanges and demonstration blocks in the smaller libraries; and, if possible, providing small libraries with some volumes.

Materials in Languages Other Than English

One of the specific questions this study was intended to answer was the need for alternative format materials in languages other than English. The findings indicate a very small demand, although the precise figures are impossible to calculate.

It is not that the overall demand for large print and Talking Books in other languages is so small, but rather that the demand is highly segmented among numerous languages. Table 6.2 illustrates the problem by presenting selected data about mother tongue from the 1981 Census of Canada.

TABLE 6.2

SELECTED DATA FROM 1982 CENSUS OF CANADA:
MOTHER TONGUE IN ALBERTA

<u>Mother Tongue</u>	<u># of Albertans</u>	<u>% of Albertans</u>
English	1,810,545	80.9%
German	91,480	4.1%
Ukrainian	68,130	3.0%
French	62,145	2.8%
Chinese	28,910	1.3%
Other languages (less than 1% each)	176,515	7.9%

If we assume, for the moment, that the mother tongue percentage in the Alberta population can be applied directly to the print limited population (23,062) to generate estimates of the demand for alternative formats in languages other than English, we obtain the following figures:

German	945
Ukrainian	692
French	645
Chinese	300

However, it is patently obvious that these figures do not truly represent demand for alternative format materials in languages other than English. They are certainly overestimates. First of all, mother tongue refers to the language one grew up speaking at home. It does not mean that one also does not speak English. Similarly, speaking and reading a language are two different things, as one nursing home pointed out to us. They obtained some books in Ukrainian for some of their elderly patients who were more comfortable with Ukrainian than English. However, the patients showed little interest in the books. This experience suggests that development of large print foreign language materials intended for the elderly might frequently go unused. There is a high probability that if the elderly persons grew up outside of North America in the early 20th century, they may not be able to easily read their native language. Finally, and most importantly, it is reasonable to assume that individuals who do not read English are much less likely than the population as a whole to use Alberta public libraries.

Studies have shown that selection is an overriding factor in whether or not people use libraries (Ballard, 1981). People simply will not use libraries if they perceive a very limited selection of materials. This notion makes a great deal of sense if one considers the effort

that, for instance, a vision impaired Chinese person would have to put forth to get certified for Talking Books, knowing that there may be only a few titles to choose from over the next several years. Similarly, it is hard to imagine a disabled, elderly Ukrainian person travelling to the library or asking a family member to go if there are only a few large print titles in Ukrainian.

One can only conclude that purchase of Talking Books and large print materials in languages other than English would only be worthwhile if it is possible to obtain a reasonable selection of titles in any particular language. Given the figures for Alberta, German and Ukrainian are the two languages for which there would be a relatively significant demand. However, we do not recommend development of foreign language alternative format materials as a high priority for ALSH.

Miscellaneous Other Materials

The previous subsections have dealt mainly with visual and cognitive limitations. Serving the reading needs of people who have other physical limitations--e.g., endurance problems, lack of muscular strength, coordination problems and spasticity, and missing hands and/or arms--requires a somewhat different approach. Large print books tend to be inappropriate, because they are heavy, and the disabled individual may have the same or more trouble coordinating Talking Books cassettes and playback machines as using books. Most solutions involve technical aids and personal service (to be discussed in subsequent subsections), but we did receive a few suggestions regarding special materials from agencies and institutions. The suggestions included: putting spiral bindings on books and magazines so that they don't easily fall shut; plasticizing materials, especially flimsy and heavily used ones (e.g., magazines and newspapers) so that people with spasticity do not tear pages; and having lightweight materials (e.g., paperbacks) for people with strength and endurance problems. Obviously, some of these suggestions are in conflict with one another (e.g., plasticizing increases the weight of a volume), and any of the suggestions would be extremely expensive to implement.

In the focus groups and agency interviews, some individuals expressed a need for video tape and filmed materials for people with comprehension and cognition problems. However, the respondents generally acknowledged the expensive nature of providing such materials, feeling them to be a useful "frill" rather than a necessity. In one case, though, an individual suggested films or video tapes of fiction in sign language for the deaf illiterate population. She suggested that she would be able to provide volunteer interpreters if a library or ALSH could arrange for the taping or filming.

None of our respondents brought up the idea of a radio reading service. Although the literature provides several successful

examples of such services, we suggest that the expense during a time of economic recession, the needs for more basic materials and services, and the fact that this service was not brought up by any of our informants,* are three reasons why the idea should be set aside for the time being.

One individual, however, vehemently expressed a need to use cable television more effectively, and felt that community cable systems ought to include special programming for people who are print limited because of comprehension and cognition impairments.

* We brought up the idea during focus groups and interviews. No participants brought it up independently, and although people were pleased with the idea, there was no feeling expressed that it is an immediate need.

6.2 PROVIDING AND EDUCATING ABOUT AVAILABLE TECHNICAL AIDS

People use alternative formats because they have extreme difficulty or an inability in using reading materials in conventional formats. But sometimes a technical device can reduce or eliminate the disability with respect to the reading materials. The devices which are available vary in their usefulness, depending on the precise nature of a person's impairment(s) and on personal preferences. Devices also vary in their effectiveness, sophistication, and cost.

Focus group participants, agency representatives, librarians, institutional representatives, and the literature all stressed the importance of technical aids in reducing handicaps of conventional formats. Although a few sources praised highly complex (and expensive) equipment such as the Kurzweil Reading Machine, disabled individuals themselves and most other informants emphasized the importance of simple and inexpensive aids such as magnifiers, high intensity lighting, reachers, and bookstands.

A public library can equip itself with a variety of technical devices for use and try-out by visiting patrons, and also can maintain a supply of inexpensive devices for loans. Equipment such as a Kurzweil Reading Machine or the less (but still) expensive magnifying machines which enlarge print and project it on a television-like screen allow some visually impaired and blind patrons to use regular materials such as periodical and reference works, materials they otherwise cannot use. The chance to use such sophisticated equipment is also a valuable service because it allows a disabled person to try out expensive equipment before making a decision to purchase one for home use.

Equipping the library with such major equipment is an expensive proposition and one which, in the short run, will serve a small and select group of patrons. The Calgary Public Library's Outreach Department has purchased some magnifying machines and has found that they receive a fairly low level of use. Even the Mid-Manhattan Library in New York City reported only twelve regular users of its Kurzweil Reading Machine after over a year of service. Purchase of such equipment can only be justified by the opportunity to access that it provides and as a long term investment.

There are less expensive devices, however, which can be provided for use in the library. Bookstands, magnifying lamps, and small magnifiers are three cases in point. These are the sorts of devices suggested most often by the informants to our study. Having small technical aids available for use in the library serve purposes similar to those of the more expensive equipment, but at a low cost to the library. Again, the Calgary Public Library has been a pioneer in this area, and has found that its smaller devices get more use than its expensive equipment.

A library can also lend the smaller devices for patrons' use at home (or in an institution). According to the Calgary Public Library's experience, patrons often purchase their own devices after trying them out at home.

ALSH should serve Alberta's public libraries in this area by researching available aids and devices so that the libraries have purchasing information. By undertaking the centralized research function, librarians need not constantly duplicate one another's efforts. It is important that ALSH begin this task by finding out that information and experience already gained in the larger public libraries, some of which have devoted extensive effort to the task of researching aids and equipment.

The following is a list of sources which ALSH could use to obtain state-of-the-art information about aids*:

Rosemary Murphy
ABLEDATA System
Children's Hospital at Stanford Rehabilitation
Engineering Centre
520 Willow Road
Palo Alto, California 94304
U.S.A.
(415) 327 - 4800

Bulletin of Prosthetic Research
Veteran's Administration
Office of Technology Transfer
252 7th Avenue
New York, New York 10001
U.S.A.
(212) 620 - 6659

NARIC Database
The Catholic University of America
4407 8th Street N.E.
Washington, D.C. 20017
U.S.A.
(202) 635 - 5822

Mary Vasey
Canadian Rehabilitation Council for the Disabled
1 Yonge Street
Toronto, Ontario

* Provided by Linda Barr, Technical Resource Library, Alberta Childrens Hospital.

M. Linvill
Sensory Aids Foundation
399 Sherman Avenue
Palo Alto, California 94304
U.S.A.

Another way in which ALSH can serve public libraries is to develop a demonstration collection of technical devices which can be loaned to libraries to aid them in their own purchase decisions.

A third area concerns information about and, possibly, provision of technical aids related to Talking Books use. Berkowitz, et al., (1979, v. 2, pp. 123-134) found that over half of the population which is print limited has one or more compounding limitations which make Talking Books use difficult or impossible. For example, 5% of the print limited population is confined to a bed, 25% is hard of hearing or deaf, and 15% is in poor health. The authors mention (v. 4, pp. 74-75) that there are adaptive devices which can reduce the problems in using Talking Books--headsets which can amplify for people with hearing problems, and "pillow phones" and remote control devices for people who are bedridden. Other devices may also be available.

ALSH should investigate the availability of adaptive devices to enable Talking Books use and forward the information to public libraries. Two sources for information are the Alberta Rehabilitation Council for the Disabled in Edmonton and the NLS of the Library of Congress in Washington, D.C. In order to help libraries determine the value of such devices, it would be helpful if ALSH would purchase a limited number of each type of aid for try-outs by library patrons. Berkowitz, et al. (1979) noted some unhappiness with the quality of certain devices.

6.3 PROVIDING PROGRAMS OF ONE-TO-ONE SERVICE

Even with a large selection of Talking Books, large print, and technical devices, a large proportion of the print limited population will not have the same access to library materials as does the general public. Many reference materials*, periodicals, and infrequently requested titles will not be available in special formats.

- * The World Book Encyclopedia has recently been issued in Talking Books format with a special playback machine. The Calgary Public Library has acquired it and has found that it opens whole new worlds to some print limited individuals. For example, one blind patron has been visiting the library regularly to read the encyclopedia straight through. His enthusiasm is a result of the fact that such reference material has never been available to him before. However, it is unlikely that a large selection of reference material will come available in alternative formats in the near future.

Some individuals will never be able to use any sort of print, even large print with the aid of magnifying devices. Thus there is a need for personal reading services.

The need for personal reading services was made very clear in our focus groups. Even a young, social, print limited individual cannot always find a friend or family member to read to him when he needs some reference information, would like to hear a newspaper or magazine, or simply wants to read a book which is not available in an alternative format. For example, one of the focus group participants was a young woman whose reading companion accompanied her to the group. They share specialized interests in fiction and read avidly. However, she noted, "He can't always be reading to me." There are times when asking a friend or relative to read feels like an imposition. The problem is likely to be much more severe among elderly persons who may be more socially isolated. Even in institutions, where the isolation may be less severe than among disabled elderly persons living alone, there is a problem in getting assistance with reading. About one-third of the respondents to our institutional survey said that the lack of people to help with reading is a minor barrier to reading at their institution; another one-third said it is a major barrier.

There are several types of needs for one-to-one assistance. For a few people the assistance may be as simple as changing tapes in the playback machines. For others, there is a need for patient, repeated instruction on using the machines. Reading for pleasure is the most obvious need for one-to-one service. A less obvious need, and one which our focus group members pointed out, is the need for finding and reading reference material. The general public uses libraries for obtaining information useful in daily living, e.g., consumer information to help with a purchase, business information to help make investment decisions, travel books to help plan a holiday, cookbooks, gardening books, and so forth. This entire area is closed to people who are unable to use conventional formats because the materials are unusable without someone to find and read the materials.

There are examples in Alberta of services provided by libraries to fill some of these needs. Out of necessity the services rely on volunteers. The Calgary, Edmonton, Grande Prairie, and Lethbridge libraries all use volunteers to deliver books and sometimes read to patrons. In order to succeed, the librarian administering the program needs special skills in recruiting, training, and maintaining volunteers. As some of these libraries have demonstrated, a volunteer program can have more strengths than weaknesses--low rates of turnover, high commitment, regular one-to-one service. But it also requires the skills and the time to effectively keep the program running smoothly. This is where ALSH can provide much needed assistance, especially to smaller libraries. The attitude that volunteer programs do not work, that volunteers are unreliable, is a misconception that must be broken, and ALSH can indirectly serve

the disabled population by educating librarians about how to run a successful volunteer program. ALSH can draw on those librarians who have been successful in this area as one source of information for preparing to educate other librarians who have not (or who have not tried). However, it must be stressed that development of such programs does take skill and time.

7. HANDICAPS OF THE LIBRARY ENVIRONMENT: PHYSICAL ACCESS AND FACILITIES

Conventional materials are not the only barriers to equal access to public libraries. Disabled persons often cannot get to the library, and/or use the facilities within the library. These handicaps of physical access and facilities are a result of the conventional, non-adapted infrastructure of libraries for people who have impairments of mobility, coordination, strength, endurance, dexterity, and/or sight.

7.1 ESTIMATES OF THE NUMBER OF ALBERTANS AFFECTED BY PHYSICAL ACCESS AND FACILITIES HANDICAPS

A conservative estimate is that about 53,000 Albertans are affected by physical access and facilities handicaps. This estimate is derived by applying figures obtained in the recent study of disabled population in Ontario (Ontario Ministry of Health, 1982) to the Alberta population.

The estimate is based on an application of the Ontario figure that 11.29% of the total provincial population has an impairment, and 54.5% of those who are impaired experience a handicap in some aspect of their daily lives. This yields a base figure of 117,468 "handicapped" Albertans.

Next, we selected those functional limitations which are likely to result in a handicap of a library's physical facilities (or access to them), and again applied the Ontario figures regarding proportions within the handicapped population. These proportions and the resulting Alberta figures are shown in Table 7.1.

TABLE 7.1

ESTIMATED MINIMUM NUMBER OF ALBERTANS
POTENTIALLY AFFECTED BY HANDICAPS OF
PHYSICAL ACCESS AND FACILITIES
(ASSUMING 117,468 "HANDICAPPED"* ALBERTANS)

<u>Primary Functional Limitation</u>	<u>% of Handicapped</u>	<u>Estimated Number of Albertans</u>
Spine/Trunk	12.6	14,801
Foot	3.3	3,876
Arms/Hands	5.1	5,991
Musculoskeletal, multiple	8.4	9,867
Sight	4.7	5,521
Balance	0.9	1,057
Endurance	0.3	352
Knee	2.3	2,702
Hip/Pelvis	2.3	2,702
Leg	5.1	<u>5,991</u>
TOTAL		52,860

* Based on data from Ontario Ministry of Health, 1982, p. 35.

The estimate of just under 53,000 is a minimum conservative estimate because it includes only those individuals whose primary limitation could affect library access and use of facilities; it does not include those multiply handicapped persons whose secondary, tertiary, etc. limitation would be relevant, but not their primary limitation.

Using data concerning all relevant limitations yields the figures presented in Table 7.2. Comparing Table 7.2 with Table 7.1, above, it is clear that the figure of 53,000 is a low estimate.

TABLE 7.2

ESTIMATED NUMBER OF ALBERTANS WITH PARTICULAR
FUNCTIONAL LIMITATIONS RELEVANT TO
HANDICAPS OF PHYSICAL ACCESS AND FACILITIES
(ASSUMING 117,468 "HANDICAPPED"* ALBERTANS)

<u>Functional Limitation</u>	<u>% of Handicapped</u>	<u>Estimated Number of Albertans</u>
Spine/Trunk	22.2	26,078
Foot	7.4	8,693
Arms	7.5	8,810
Hands	7.9	9,280
Musculoskeletal, multiple	14.5	17,033
Sight	11.6	13,626
Balance	3.2	3,759
Endurance	2.9	3,407
Knee	6.6	7,753
Hip/Pelvis	4.9	5,756
Leg	12.7	14,918

* Based on data from Ontario Ministry of Health, 1982, p. 37.
Please note that these figures are not additive, because
some individuals have multiple limitations and so are included
more than once.

According to the Ontario data, 41.1% of all handicapped persons have trouble with entry into or exit out of buildings. This would translate into 48,279 Albertans who are handicapped when trying to get into libraries, and to that total can be added those who can get in and out, but have other problems with the facility (e.g., manual dexterity, vision). Similarly, 53.7% of all handicapped persons in Ontario expressed difficulty in generally participating in recreational and social activities (of which using the library is one). This translates into over 60,000 Albertans.

In summary, it is safe to say that at least 53,000 Albertans, or about 2.3% of the provincial population, are very likely to be unable to use libraries independently unless those libraries are specially adapted for accessibility (along with auxiliary services--such as transportation and special parking--being available).

7.2 THE NATURE OF PHYSICAL ACCESS AND FACILITIES HANDICAPS AND IMPLICATIONS FOR LIBRARY SERVICES

The focus group participants, the agencies we surveyed, and the literature had a great deal to say about physical access and facilities handicaps. However, it is noteworthy that literature on special library services, until recently, has emphasized handicaps of conventional formats at the expense of other barriers to using a library normally.

These handicaps may be thought of as weak links in a chain. If any one link is weak, use of the chain (i.e., use of a library) may be impossible.

The first link is the ability to leave one's own residence. According to the 1982 Ontario Ministry of Health data, 24.6% of the handicapped population (i.e., 28,897 Albertans) either cannot leave their own residence, or require special equipment or human assistance to exit from their residence. The implication for library services is a great need for homebound and institutional services, wherein the library delivers materials to the patron's place of residence.

The next link is transportation to the library. In Ontario, 28.6% of the handicapped population reported serious transportation problems. If similar proportions apply to Alberta, it is obvious that the need for "homebound" reader services are even greater, not because people's physical conditions necessarily keep them homebound, but that transportation opportunities are inadequate. We suspect that the proportions would increase in cold, wintry weather.

The next link is getting from the transporting vehicle to the library's location. Although we do not have any figures for this aspect, focus group and agency participants made it clear that this is the link which is often the weakest. If the transportation mode is a good parallel system (i.e., adapted vans), there can be door-to-door service.* However, there must be a place at the main entrance to a library where a van can park and which has room for the ramps and lifts that are part of an adapted van. With conventional public transportation--if it is available and if the person is able to use it--the distance to negotiate between the library and the bus or LRT stop may be too great for the person (especially the elderly and other people for whom walking is a great effort; and especially in very cold and/or icy weather). The third option, travelling in a private adapted van requires that there be wide parking places close by the library itself. A normal parking space--even if it is reserved for the handicapped--will not suffice. A

* Agencies and focus group participants noted that even in the two major cities in Alberta the parallel transportation systems have major problems (e.g., too few vans, limits on the number of times per month one can use the service).

width of approximately one-and-one-half times a normal parking space is necessary for lowering a wheelchair out of the van. Unless the disabled person has an electric wheelchair, a distance of more than a block between parking space and library can be too taxing. Finally, any unramped curbs on the way will form a "weak link."

Once at the library, the chain may be broken by stairs, doors which are heavy, doorways which are narrow, or turnstiles. Attention to every detail in physical adaptations is absolutely essential. For instance, a librarian at one Alberta library told us that the ramp which had been installed at the library was not being used. This librarian construed this fact to be indicative of no demand for library services among people in wheelchairs. However, when we were interviewing an advocacy group in that same community, the representative complained that "we can't use our library because the ramp is at too steep an angle."*

Inside the library, the disabled patron may face a host of other barriers--narrow aisles, books which are too high or too low to see or reach, tables which do not accommodate a wheelchair, signs which a person with vision problems cannot read, non-adapted washrooms (extremely important because people with certain disabling conditions have poor bowel and/or bladder control), catalogues which require manual dexterity to use, no way to carry books around (particularly a problem for individuals in a manual wheelchair, with spasticity, or who are using a cane, crutches, or a walker), no place to sit while browsing the shelves (a barrier for people with strength and endurance problems), dust and mould in the atmosphere (critical to people with respiratory ailments), just to name a few.

Again, attention to detail is essential. For example, individuals with reading disabilities are often disoriented by hanging signs. Fluorescent lighting may trigger a seizure among epileptics and may impair the vision of some people with cerebral palsy (one informant described it to us as "the feeling that your forehead is coming down to cover your eyeballs").

Some public libraries report that they have made various adaptations to their facilities. The Calgary Public Library (Central) is the only one in Canada with a completely accessible section for the use of disabled persons.**

* This, by the way, illustrates the importance of consulting with disabled persons when making adaptations.

** Even it has its problems. In addition to the fact that it is only one section, the elevators are not equipped with tactile controls and indicators so that a vision impaired person can use them. This problem is being rectified by the Calgary Public Library.

What can ALSH do to promote the strengthening of the weak links and a reduction of the barriers? In some cases--for instance, the lack of adequate adapted transportation--the answer is "nothing." However, ALSH can promote improvements in homebound readers services and in adaptations to the libraries themselves by educating the librarians about what needs to be done and how it can be accomplished. ALSH can provide to libraries copies of the U.S. Library of Congress Standards (A.L.A., 1979) and/or the less detailed paper on "Physical Access" (Kidd, 1981, an appendix in Swindley and Kidd, 1981, for the Australian Library Promotion Council). Until similar Canadian standards or guidelines are available, these documents will do very well as reference works for librarians. It cannot be realistically expected that most Alberta libraries--especially the smaller ones--will voluntarily undertake expensive renovations. However, such information can both give librarians an understanding of the major physical barriers to using their libraries as well as provide guidelines for libraries which are building or remodelling.

In addition, the following are the specific comments and suggestions we obtained from our research. These are all areas which ALSH can promote at public libraries.

- In the absence of physical adaptations, libraries must be prepared to provide personalized service. Besides homebound readers services, the library staff must be trained to be sensitive and responsive to the needs of disabled individuals in the library (more will be said about this in Section 8.2). At times, this may mean helping to identify materials, gathering them from shelves, reading passages or Tables of Contents aloud, helping with check-out of materials, and so forth. One focus group suggested that larger libraries should train staff who work near the front entrance to recognize disabled individuals when they enter and how to approach them to determine if they need any special assistance.
- Libraries should begin to look at alternative methods of cataloguing and locating materials, methods which will be usable by various disabled groups. Mentally handicapped individuals will not be able to find materials of interest to them (e.g., "coffee table" books with heavy pictorial content) using traditional systems. Several informants, as well as some literature, suggested color coding with large colored signs on shelves as well as colored stickers on the books, to help people with low vision and cognitive limitations find materials. Other informants suggested the use of large, simple picture symbols.
- When the library prints information leaflets or posts instructions on using some aspect of the library, the print should be large and well spaced.

- A representative of a major Alberta seniors' agency suggested that libraries should circulate collections of materials through local seniors' centres. Not only will this get the materials to people who would not easily be able to use the library, but such groups are often "program short," and in need of the materials.
- Libraries should avoid what one informant called "token gestures" --special programs which are of low quality. She gave the example of a film program for seniors that used to be run at a major public library. The informant reported that the selection of materials was poor and the equipment was always faulty.
- Because transportation is such a problem, two informants from a major gerontological organization suggested what they called "reverse outreach." Rather than taking a mobile unit of books out to a seniors' centre or residence, a library should use a mobile service to bring groups of seniors to the library. This suggestion could easily be extended to other groups. If the library does not own an appropriate transporting vehicle, it could work with community agencies to locate one owned by an agency (or the community at large) to provide special group transportation periodically.
- Libraries should attempt to ensure that lighting is glare-free. There should be special reading areas with bright, glare-free, non-fluorescent lighting.
- All directional and informational signs should be placed at eye level. White letters and numerals on a dark background, with generous spacing, may be the most easily readable. It is especially important to use standard rather than decorative lettering.
- It is important to have good solid chairs which are easy to get out of.
- Edges of stairs should be marked with a contrasting colour.
- Catalogues and other materials necessary for using the library should be able to be reached from a wheelchair.
- Catalogues for large print books should also be in large print.
- Although travel in a freight elevator is not the ideal, it may be the only way that some individuals can get into and around in the library. Staff should be aware of availability of freight elevators for disabled persons.
- There should be at least one table which can accommodate a wheelchair rather than conventional chairs (i.e., about four inches higher than an average reading table).

- Large libraries should have visual as well as auditory signals for general and emergency information for deaf persons (e.g., fire alarms and announcements of library closing).
- There is a device called a "phonic ear"* which should either be available to hearing impaired children or recommended to their parents for story hours. It is a device which carries the voice directly from the story-teller to the ear of the hearing impaired child. Hearing aids pick up all sorts of extraneous sounds. For example, someone tapping on a table nearby could prevent the child from being able to hear. The phonic ear remedies the problem.
- Librarians must be trained to recognize and respond to an epileptic seizure. Although it is important to realize that seizures are relatively rare these days, about 5% of epileptics cannot control seizures through medication. One library reported to us an instance in which an epileptic who collapsed from a seizure was mistaken for a drunk, so the possibility is obviously very real. Open, uncluttered, carpeted areas are the ideal environments for epileptics prone to seizures, so that they do not injure themselves. However, we should point out that installation of soft, cushioning carpeting in a library would be a huge barrier for people in wheelchairs.
- The provision of lightweight carts which could either be pushed by a wheelchair or by hand, to collect books from the shelves, would help people with arthritis and strength problems as well as those in wheelchairs.
- Slanted bookstands located periodically in the stacks areas would allow people with strength and coordination problems to be able to flip through books, to help with selection in a normal fashion.
- Books should be shelved loosely.
- If libraries have spare shelf space, they should avoid using the very high and very low shelves, which are out of reach for many disabled persons. People in wheelchairs cannot reach the high shelves, and people with arthritis and other joint problems cannot bend down to the low shelves. The same applies to card catalogue drawers. If the library must use the very high and low shelves, it should supply simple reachers that could be used to take books off the shelves.
- Most informants to this study endorsed decentralized special and adapted services in communities large enough to have branches as well as a main library. This is because of the prevalence of
- * Contact the Central Alberta Society for the Hearing Impaired in Red Deer for further information. This is the group which made the suggestion.

transportation to and parking problems at a downtown library. Also, several people argued, a disabled person is more likely to get personal service in a smaller library.

- There were definite differences of opinions among informants concerning the implications that computerized cataloging and reference systems will have for disabled patrons. Some felt that they would increase accessibility whereas others felt that they would be terribly intimidating and thus discourage library use.
- Ramps and stairs must have handrails.
- Important public facilities, such as fire alarms and telephones, should be accessible by wheelchair. A telephone is an absolute necessity for a person who must call for transportation home from the library.
- If the library has photocopiers for public use, it should select ones which are low enough to be operated from a wheelchair (this includes the coin slot).
- Libraries should have plenty of signs located throughout the library inviting people to ask the staff if they need any assistance.
- Non-disabled patrons often use the library to gather information on a specific topic for use in a school or business related project, or for personal use (e.g., investments, purchase decisions, hobbies). The research may take several hours, with a little help from the library staff. For a disabled person, however, the task may either be impossible or take days of work. There is a real need for intensive personal assistance, but disabled persons told us that they will not "impose" on librarians by requesting the amount of assistance that they really need. A library can deal with this need by posting signs which offer in-depth assistance by appointment. The actual assistance can be provided by knowledgeable volunteers instead of or in addition to library staff.

8. HANDICAPS OF THE LIBRARY ENVIRONMENT: COMMUNICATION

Judging by the sheer amount of emphasis that the literature, the agencies, and focus group participants devoted to the area of communications, this is the most important section of this report. Effective communication is the absolutely essential basis of effective and well used services for disabled persons.

In this section we are defining the term "communication" very broadly, to include its affective as well as literal components. That is, communication is not only the ability of the library and the patron to exchange factual information. It is also the attitudes and emotions which are conveyed along with the factual information. For example, a learning disabled person who walks into a large, busy main library in a city may feel, more than anything, that the jumble of incomprehensible (to him) stimuli is confusing and intimidating. That is a part of the communication that the patron receives from the library. If a person in a wheelchair is the recipient of repeated furtive glances from library staff, that too, is communication--communication that the library staff is uncomfortable with his presence. If a person with a speech impairment is spoken to as if he is stupid, that is a communication--communication that the staff is not knowledgeable about communication disorders, assumes low intelligence, and therefore will not be able to assist him properly. In this section, we detail the potential problems in communication and what libraries can do to ensure that these potential problems do not manifest themselves.

8.1 THE TOP LONG-TERM PRIORITY: COMMUNICATING THAT THE LIBRARY IS FOR EVERYONE, INCLUDING DISABLED PERSONS

Imagine, for a moment, the fairy tale situation in which a library receives a huge financial bequest for purposes of making it as accessible to disabled persons as it is to the general population. This bequest allows the purchase of the widest possible selection of alternative format materials and technical aids; complete re-modelling for physical accessibility; the purchase of mobile units and adequate staffing, both to bring individuals to the library and take the library to them; the money even provides for the costs of professional, widespread advertising. Will all of these ideal services be used by the eligible population? From what the agencies, focus groups, and libraries told us, the answer is a definite "No."

Most disabled persons will not take advantage of the new services, even in the same proportions that the general public uses libraries. They will not patronize the services because they are not accustomed to thinking that public libraries are for them; because they have

managed without libraries in the past and will not realize what use libraries could be to them; because they are completely unfamiliar with libraries and may feel intimidated and afraid to ask very basic questions about using a library. This is the message clearly delivered by our information sources, a message qualified only to the extent that an elite group of highly educated disabled persons who have used libraries in the past would use the new services.

This is certainly not meant to be an argument for the status quo. Rather, it is a realistic, rather than an idealistic, view. In the short term, new and innovative services, materials, and equipment will not be used by most people who could benefit by them. It is only in the long run, over a period of a decade or longer, that the level of use will begin to approach the level of potential need. Thus the installation of services, materials, and equipment is an investment in the future. If ALSH, a librarian, and/or a library board optimistically expect immediate, heavy use, they are bound to be disappointed. Even worse, they are likely to reduce or eliminate the innovation before giving it a reasonable chance to prove itself, assuming that the lack of use means it is not needed. An essential role of ALSH is to help educate the Alberta library community to cultivate reasonable expectations.

This is not an easy task. A librarian who has been able to convince the senior administration and board to fund special services told us that he/she tried to instill realistic expectations. Nonetheless, he/she is sensing growing unhappiness that the new services have not been heavily used. Although he/she emphasized the long term nature of such services, the message did not get across effectively. It is a message that needs to be continually restated.

There are certain steps that libraries must take in conjunction with aiming for equal accessibility. The most important step is to form strong, ongoing liaison with schools and with parents of disabled youngsters to ensure that disabled children get positive, regular contact with the public library. This recommendation applies equally to those children who are being mainstreamed and those who are in special classes or schools.

The school library is a sheltered environment, especially for those children going to special schools. For example, in the library of a school for deaf children, the staff will be fluent in sign language. In a school for mentally handicapped or learning disabled children, the library will have specialized materials and specialized staff. In a school for physically disabled children, the library will be specially adapted. At the public library, in contrast, the facilities services will be geared to the general public rather than a specialized population. The public library may also be larger and more diverse than the school library. And, perhaps most importantly, the disabled patron is in the minority at the public library and may feel self-conscious about that. The net result is--

from what we were told by agencies and focus groups--that the last contact disabled persons may have with a library is when they leave school. They are simply unprepared to function in a public library.

To put an end to this syndrome, public libraries must begin to lure disabled children and their parents and teachers and ensure that the children--at an early age--are comfortable in and knowledgeable about the library. (Similarly, library staff will become more knowledgeable about and comfortable with disabled patrons--the learning will go both ways.)

Children should be brought regularly to the library and, as they grow into their teenage years, should be introduced to all adult library services. They should be given exercises that give them practice and confidence in using the library and also free, unstructured time to explore and browse. Additionally, the older children should be occasionally brought together with staff to discuss issues in using the library, so that problems and shortcomings can be identified and remedied.

Forming and maintaining the liaison with schools and parents which will ensure regular, intensive familiarization and refamiliarization with the library is probably the single most important expenditure of resources a library can make in any plan to develop equal access for disabled persons. In the process the library will learn more and more about how it needs to adapt its services, while future generations of disabled persons will be willing and equipped to use those services.

A similar need exists for disabled elderly people. Those who have been regular library patrons all their lives are likely to be familiar with the library's special services, provided that the services have been continually publicized in the library. However, people who have not been regular library users and who become disabled in their old age may have the desire to read and/or to have materials in special formats, but may be unfamiliar with the use of the library. Further, they may have a low educational attainment and "old fashioned" values which make them hesitant to ask about using the library. One agency explained it to us this way:

They are often too shy to admit they don't know how to find things. If they are hard of hearing, they may be too shy to ask you to repeat yourself. If they have vision problems, they may not want to admit it.

For this reason, agencies concerned with the elderly suggested that public libraries liaise with seniors' groups and bring them to the library for orientation to the services and how to use them.

A more general need exists to develop orientation programs and materials to teach disabled persons to use the library. At the same

time, library staff must cultivate an attitude that welcomes inquiries and shows patience. Basic knowledge about what the library has to offer, how to find materials, and how to check out books are generally missing within the disabled population, according to the agencies that we interviewed.

The library can publicize orientation and educational sessions through agencies and organizations which serve disabled persons. It would be best to allow such organizations to schedule their own private small group sessions, besides having "open to all interested persons" orientations. Orienting groups of people who already know one another can go a long way toward reducing fear and shyness about coming to the library.

8.2 DEVELOPING AND COMMUNICATING POSITIVE STAFF ATTITUDES

Attitude change is a slow and difficult process. In cases where attitudes are well meaning and friendly, but based on mistaken beliefs (e.g., "mentally retarded people can't learn to read"; "all people with cerebral palsy are mentally retarded"; "you have to treat disabled people like children") attitude change depends on providing the correct information. However, when negative attitudes are based on deep-seated fears, irrational beliefs that cannot be eliminated in spite of the facts, or negative past experiences which have made an indelible impression, attitude change is much more difficult, perhaps impossible.

Practically all agencies and focus group members noted negative attitudes--or the fear of negative attitudes--as a major area for libraries to work on. The type of attitudes they were referring to are those which can be changed through education about and experience with disabled persons. In all fairness, no one reported an actual bad experience with a public library in Alberta. On the contrary, people who had reported on experiences with libraries described library staff as generally "friendly and helpful." Nonetheless, many feared the possibility of bad experiences with librarians simply because disabled persons have had so many negative experiences with the "general public," of which librarians are a part.

Without specific education, training, and experience, librarians are bound to have gaps in knowledge and misapprehensions about disabilities. This can result in inadequate, inappropriate, and/or alienating service to disabled persons. More specifically, some of the problems that can result are:

- a patronizing, unconsciously condescending or pitying attitude toward disabled persons;
- extreme discomfort which can interfere with factual communication and can alienate the

patron (or cause the librarian to avoid the patron);

- denial of the need for library services for disabled persons (this often stems from the belief that there are special agencies "out there" who are serving the needs of "those people," and an implicit denial that the "public" in "public library" includes disabled persons)*;
- a tendency to underestimate the abilities of disabled persons, and therefore "censoring" services and materials for difficulty;
- a lack of the knowledge of the technical devices or library facility/service adaptations that could benefit disabled patrons;
- mistaking disabled people for drunks or drug abusers; and
- assuming elderly persons to be "slow" or "senile."

ALSH can assist the process of education by providing libraries with copies of this report and other informative materials, as well as supplying (and updating) a bibliography of materials for librarians. Also, ALSH should inform Alberta librarians of any conferences, workshops, continuing education courses, etc. which are coming up.

ALSH can also promote education informally through its field staff and, more formally, through the development of materials and in-service training programs. However, any actual training materials and sessions should be developed by working with organizations of disabled persons.

ALSH should also strongly encourage libraries to get staff training from local organizations of disabled persons. Most such organizations are willing and equipped to conduct workshops with professionals--such as library staff--to provide accurate information, promote sensitive attitudes, and give staff a chance to interact with disabled persons on a professional basis. The actual experience of being taught by a disabled person can be as valuable as the factual information that is presented.

* We definitely ran across this attitude in one of our library interviews.

8.3 TECHNICAL ASPECTS OF FACTUAL COMMUNICATION

In addition to the affective elements of communication, which could involve any disabled individual, the factual elements of communication may present a handicap to disabled persons with hearing impairments or communication disorders. Depending on the nature of the physical impairment, the person may be unable to use the telephone to call the library; be unable or have difficulty communicating with speech or writing; or be unable or have difficulty receiving verbal or written messages.

One agency source put the number of people with hearing or communication disorders at 1% of the total provincial population (over 23,000 persons) excluding those who have speech or hearing disorders due to a learning disability. Application of the 1982 Ontario Ministry of Health data to Alberta lends credence to this estimate, yielding an estimate of over 19,000 people with a functional limitation on hearing and over 4,000 who have a speech limitation. To these figures can be added an unknown number of people with learning disabilities which limit their ability to process and/or produce verbal and/or written information.

The major suggestion which came out of our agency interviews and focus groups was that librarians be trained to recognize, understand, and deal with hearing and communication disorders. It is easy to mistake some such individuals for people of low intelligence or people who are inebriated (because of slow or slurred speech). Not only could this cause great embarrassment to the disabled person, but it could also result in poor or inappropriate service to him.

A second suggestion was to have special TDD telephone facilities in the library for use by deaf persons. This would allow deaf persons to phone the library for information as the general public is able to do. One of the major public libraries in Alberta has installed a TDD and has found that it provides a public service that had not been originally anticipated. Deaf persons who cannot afford their own TDD come to the library in order to use it.

Finally, one agency representative suggested that libraries have a board at information desks with pictures that symbolize common questions in a library. This, he suggested, would allow people with communication disorders to indicate their questions by gesturing toward a particular symbol or set of symbols.

9. LIBRARY SERVICES IN LONG TERM CARE INSTITUTIONS

9.1 LONG TERM CARE INSTITUTIONS IN THE PROVINCE AND IN THE SAMPLE SURVEY

Between 20,000 and 25,000 people are patients in Alberta health care institutions at any given time.* The types of institutions include active treatment hospitals, federal hospitals, rehabilitation hospitals, auxiliary hospitals, nursing homes, psychiatric hospitals, and geriatric institutions. The vast majority of institutions are active treatment hospitals, auxiliary hospitals and nursing homes.

For this study, we excluded active treatment hospitals--whose patients are generally short term--and focused on the two largest categories of long term care institutions--auxiliary hospitals and nursing homes. According to a recent publication (Alberta Hospitals and Medical Care, 1981), there are 3,360 auxiliary hospital beds and 7,422 nursing home beds in Alberta. The majority of patients are age 65 years or older.

Geographically, these beds are distributed as shown below in Table 9.1. Table 9.2 shows the geographical distribution of beds among the 23 institutions which responded to our sample.

TABLE 9.1
GEOGRAPHICAL DISTRIBUTION OF LONG TERM CARE
BEDS IN ALBERTA

	Nursing Homes # of Beds	Auxiliary Hospitals # of Beds	All Beds # of Beds	%
Calgary/Edmonton	4,084	2,296	6,380	59%
Small cities*	965	350	1,315	12%
Rural communities	<u>2,373</u>	<u>714</u>	<u>3,087</u>	<u>29%</u>
TOTAL	7,422	3,360	10,782	100%

* Grande Prairie, Red Deer, Lethbridge, Medicine Hat

* Source of data on numbers of patients drawn from the Annual Provincial Patient Census, November 7, 1979, prepared for the Alberta Hospital Association. Data on number of beds drawn from Background Paper to a Study of Assessment and Placement of Long-Term Care Patients, Alberta Hospitals and Medical Care, November, 1981.

TABLE 9.2

GEOGRAPHICAL DISTRIBUTION OF SURVEY RESPONDENTS*

	<u>Nursing Homes # of Beds</u>	<u>Auxiliary Hospitals # of Beds</u>	<u>Combined** # of Beds</u>	<u>All Beds # of Beds</u>	<u>%</u>
Calgary/Edmonton	572	-	997	1,569	57%
Small cities	398	200	-	598	22%
Rural communities	<u>238</u>	<u>150</u>	<u>183</u>	<u>571</u>	<u>21%</u>
TOTAL	1,208	350	1,180	2,738	100%

* Our questionnaire did not ask the "combined" institutions to break down their beds by type, so percentages within the individual columns are meaningless.

** Institutions with both auxiliary hospital and nursing home beds.

Comparing Tables 9.1 and 9.2, it is clear that our sample has approximately the same proportion of beds in Calgary and Edmonton as are found within the population of long term care beds. However, the small cities are over-represented and the rural communities are under-represented in our sample. This is because the individual institutions in the rural communities are generally small (under 100 beds), whereas they are larger in the small cities (over 100 beds). Thus, although we had nine responding institutions from rural communities, compared with only five in the small cities, the rural proportionate representation of beds in the sample is still somewhat biased. Table 9.3 provides further data about the composition of the survey respondents.

TABLE 9.3
CHARACTERISTICS OF THE
SAMPLE OF LONG TERM CARE INSTITUTIONS

	<u>Rural Communities</u>	<u>Small Cities</u>	<u>Calgary/ Edmonton</u>
Population range of communities	1,500-9,600	40,000-55,000	532,246-592,743
Median population of communities	3,493	46,393	562,495
Size range of responding institutions (number of beds)	40-102	100-150	65-322
Median size of institution (number of beds)	50	118	150
Number of responding institutions	9	5	9
Number of non-responding institutions	-	-	1

There were 23 respondents and one non-respondent, for a response rate of 96%. About one-quarter of all provincial auxiliary hospital and nursing home beds are represented within the responding institutions.

9.2 READING HABITS AND READING SERVICES IN THE LONG TERM CARE INSTITUTIONS

The majority of patients in long term care institutions are not regular readers, according to the survey respondents. About half the institutions report that one-quarter or less of the patients read regularly. Just over 15% of the institutions report that more than half of their residents are regular readers. As Tables 9.4 and 9.5 show, there appear to be relationships between community and institution size on one hand and proportion of readers on the other. In general, there is a larger proportion of regular readers in institutions located in larger communities (Table 9.4). This is likely a reflection of the fact that institutions in the larger communities have access to more proactive and extensive public library services than do institutions in smaller communities. A similar pattern appears with respect to the size of the institution itself. Larger institutions (as measured by number of beds) report a relatively larger proportion of regular readers (Table 9.5). In addition to the fact that the bigger institutions tend to be found in the larger communities, this pattern may also reflect the fact that the larger institutions can be better equipped to provide adequate in-house library services.

TABLE 9.4

ESTIMATED PROPORTION OF RESIDENTS
OF LONG TERM CARE INSTITUTIONS
WHO ARE REGULAR READERS: RESPONSES BY COMMUNITY SIZE

	Estimated % of Residents Who Are Regular Readers							
	< 25%		25-50%		50-75%		75-100%	
	#	%	#	%	#	%	#	%
Rural communities	6	67%	2	22%	-	-	1	11%
Small cities	2	40%	2	40%	1	20%	-	-
Calgary/Edmonton	3	33%	4	44%	2	22%	-	-
TOTAL	11	48%	8	35%	3	13%	1	4%

TABLE 9.5

ESTIMATED PROPORTION OF RESIDENTS
OF LONG TERM CARE INSTITUTIONS WHO ARE
REGULAR READERS: RESPONSES BY SIZE OF INSTITUTION

Number of Beds	Estimated % of Residents Who Are Regular Readers							
	< 25%		25-50%		50-75%		75-100%	
	#	%	#	%	#	%	#	%
50 or fewer	3	50%	2	33%	-	-	1	17%
51-100	5	83%	1	17%	-	-	-	-
101-150	2	29%	3	43%	2	29%	-	-
151 or more	1	25%	2	50%	1	25%	-	-
TOTAL	11	48%	8	35%	3	13%	1	4%

Reports from the survey of major libraries as well as from the institutional survey seem to indicate that--with some notable exceptions--the library services are much better and more comprehensive in the larger institutions and in the larger communities. The Edmonton and Calgary libraries, especially, have developed a strong set of services to long term care institutions, as the following two quotes from the institutional survey indicate.

[Name of a librarian] from Outreach Services at the Calgary Public Library works with me to get residents large print books and Talking Books. Two volunteers go around the home every two weeks with a "book mobile" with a variety of books, both small and large print [presumably

from the deposit collection provided by the Calgary Public Library]. We also get tapes and large print books from the Christian Record Braille Foundation in Lincoln, Nebraska. A lot of our residents love to hear the word of God. Without these services, I couldn't do it. We have 150 residents, all with different needs. The Calgary Public Library also has books in different languages--that helps some residents. I'm so grateful for these services.

* * *

The Edmonton Public Library Service for "Shut In's" comes 2x a month to each of the 3 Nursing Units with a Library cart which includes large print material. One part of the facility has 222 beds: 147 for Nursing-home patients and 25 for Auxiliary patients. We also have the [name of other part of the facility] with 100 beds mainly for patients classified as Auxiliary. At this pavilion there are few books requested from the Library Service and patients are referred to the Shut-In Volunteers for books.

There is a special volunteer from the Edmonton Public Library system who looks after the Talking Books, equipment and exchanges tapes. She visits 8 patients who have been referred to her by myself or other staff or Library Volunteers.

All Public Library Services are excellent. The volunteers are well trained and come regularly. They accept special requests for reading materials.

In July 1982 we opened a browsing library for the patients in which donated books and magazines are displayed. It has a well lit reading/writing counter and patients can take out any book or magazine without the fuss of having to sign in or out. They are requested to return the reading material. At this point we don't know how much it is used. It is serviced by our volunteers. We placed four magazine racks throughout the building [also stocked with donated reading material].

These lengthy quotes are indicative of the best institutional library service to be had in Alberta. It happens when a well equipped, committed public library works closely and sensitively with the activity director or volunteer coordinator of an institution. If such a person in an institution is not interested in promoting library services, or if the public library is unwilling or

unequipped to offer strong, regular services, residents in the institution will have severely limited access to materials and assistance for reading.

An example of the relatively poor services that can exist are illustrated by this quote from a one hundred-bed institution in one of the small cities:

The material and services available cater to the conventional type of library user. Special aids such as Talking Books and large print are presently not available through this facility. These aids are available through the local public library. The problem with this is that at least 80% of the patients at this hospital do not have access to the library, due to transportation problems and lack of assistance from volunteers or family. We feel that these aids should be available at this institution to best serve patient reading needs.

The passages quoted above were in response to an open-ended question which asked, "What services or materials currently exist to assist residents in your institutions in their reading?" We coded these open-ended responses, and found the following:

- 19 institutions (83%) mentioned Talking Books. However, one of these institutions had had a Talking Books user in the past, but not now; another five reported only one Talking Books user now; two only have Talking Books users through the CNIB (not the public library). Thus the proportion of institutions with more than one active Talking Books user getting materials from public libraries is closer to 50%.
- Talking Books use is much more prevalent at institutions in Edmonton and Calgary than anywhere else. 89% of the Edmonton/Calgary institutions have several active Talking Books users whose materials are supplied by a public library.
- 70% of the institutions report some large print materials, either in-house or supplied by the public library. A frequent comment was that large print is well used and that more large print materials are needed.
- About half of the institutions reported having their own library and/or book carts, but none elaborated on the size or adequacy of these in-house libraries.
- Only two institutions mentioned having volunteer readers.

- Two institutions mentioned weekly group sessions at which a staff member reads aloud to those residents who wish to participate.
- Two institutions mentioned technical aids, such as bedside bookstands and page turners.

9.3 BARRIERS TO READING AT THE LONG TERM CARE INSTITUTIONS

The institutional questionnaire presented respondents with nine potential barriers to reading in a long term care institution, and asked respondents to indicate how much--if at all--these barriers present themselves. Table 9.6 shows the responses.

TABLE 9.6
REPORTED BARRIERS TO READING
IN LONG TERM CARE INSTITUTIONS

	<u>Not a Barrier</u>	<u>Minor Barrier</u>	<u>Major Barrier</u>	<u>No Response/ Don't Know</u>
Vision problems	-	4% (1)	87% (20)	9% (2)
Literacy problems	26% (6)	52% (12)	9% (2)	13% (3)
Language problems	22% (5)	52% (12)	13% (3)	13% (3)
Senility/comprehension problems	9% (2)	39% (9)	43% (10)	9% (2)
Other physical problems	17% (4)	43% (10)	26% (6)	13% (3)
Difficulty obtaining materials	43% (10)	39% (9)	17% (4)	-
Difficulty finding a quiet place to read	78% (18)	17% (4)	4% (1)	-
Difficulty finding a well lit place to read	83% (19)	13% (3)	4% (1)	-
Not enough staff/ volunteers to help people with their reading	26% (6)	39% (9)	30% (7)	4% (1)

Vision problems are clearly the greatest barrier to reading in the institutions, indicating a potentially great need for Talking Books and large print materials. Almost 90% of the respondents reported that vision problems are a "major barrier" at their institutions.

Senility and other comprehension problems are the next most important barriers--"major" at 43% of the institutions and "minor" at another 39%. This indicates (as discussed in detail in Section 6.1) an especially great need for high interest/low vocabulary materials in all formats. The third greatest barrier reported by institutions is other physical problems (weakness, lack of manual dexterity, etc.).

Literacy and language problems are not often a major barrier, but present a minor barrier at a majority of the responding institutions. A lack of staff or volunteers is not a barrier for just over one-quarter of the institutions, but just under one-third report it as a major barrier and over one-third call it a minor barrier. Difficulty in obtaining materials is a major barrier for under 20% of the institutions, but is a minor barrier at almost 40%.

Finally, finding quiet and well lit places to read are not reported to be problems at most of the responding institutions.

9.4 TALKING BOOKS IN LONG TERM CARE INSTITUTIONS

There were three specific questions in the institutional survey asking about Talking Books. The questions were introduced with the following explanation of eligibility:

To be eligible for Talking Books, a person must be unable to see to read, even with corrective lenses; or, because of a physical problem, the person must be unable to use books (e.g., cannot hold a book, cannot turn the pages); or, because of an organically-based condition, the person cannot understand the printed word.

After thus explaining eligibility, we asked the respondents to estimate the number of eligible residents in their institution.

The enormous variation in the estimates was surprising, and throws them all into doubt in the absence of some objective or corroborating data. The estimates of eligibility ranged from 1.3% (a 150-bed nursing home which estimated only two eligible residents) to 80% (estimated by a large extended care facility with both auxiliary hospital and nursing home patients). There was no apparent pattern to the estimates based on type of facility or size of community, although none of the very smallest institutions (50 beds or less) estimated more than 30% of all residents to be eligible. Table 9.7 shows the estimates of Talking Books eligibility by size of institution.

TABLE 9.7

PROPORTION OF RESIDENTS IN LONG TERM CARE INSTITUTIONS
ELIGIBLE FOR TALKING BOOKS, AS ESTIMATED
BY SURVEY RESPONDENTS

Estimated Proportion of Residents Eligible	50 or Less		51-100		101-150		151 or More		All Institu- tions	
	#	%	#	%	#	%	#	%	#	%
1-9%	1	17%	1	17%	3	43%	1	25%	6	23%
10-19%	3	50%	2	33%	1	14%	1	25%	7	30%
20-29%	1	17%	1	17%	2	29%	-	-	4	17%
30-49%	1	17%	-	-	-	-	1	25%	2	9%
50-89%	-	-	2	33%	1	14%	1	25%	4	17%
TOTAL	6	100%	6	100%	7	100%	4	100%	23	100%

The median estimate of eligibility was 17%, and more than half the respondents' estimates were below 20%. If we can assume that there is accuracy in a majority (a tenuous assumption at best), then a realistic estimate of the eligible Talking Books populations in long term care institutions is less than 20%--i.e., less than 2,200 people.

One thing is almost certain--those who estimated less than 6% eligibility (5 institutions, or 22% of the sample) are underestimating. The vast majority of residents of long term care facilities are elderly and, within the general household population, about 5.5% of elderly persons are print limited in such a way that they should qualify for Talking Books (Berkowitz, *et al.*, 1979). Those individuals who are in nursing homes and auxiliary hospitals are likely to be in poorer health and have a greater number of disabilities than elderly persons in the general population.

We suspect, from the wording of some of the respondents' comments, that many institutions do not understand the eligibility requirements for Talking Books. For example, one respondent commented, "I think Talking Books should be available to people with different handicaps besides just blindness."

The lack of understanding of the eligibility requirements is not at all surprising (see Section 4.2). However, it does point to another area for ALSH to focus its education and awareness efforts. Currently, there seems to be a very small number of persons using Talking Books in most institutions. Table 9.8 shows the Talking Books readership at the sample institutions. It is notable that 65% (15

institutions) have 5% or fewer residents using Talking Books and over one-quarter (6 institutions) have none.

TABLE 9.8
NUMBER OF TALKING BOOKS USERS AT
LONG TERM CARE INSTITUTIONS

<u>Code # of</u> <u>Institution</u>	<u>Number of Beds</u>	<u>Number of</u> <u>Talking Books Users</u>
1	40	2 (5%)
2	48	3 (6%)
3	50	-
4	50	-
5	50	1 (2%)
6	50	1 (2%)
7	65	-
8	81	1 (1%)
9	95	1 (1%)
10	100	-
11	100	-
12	100	2 (2%)
13	102	8 (8%)
14	118	-
15	130	12 (9%)
16	142	2 (1%)
17	150	1 (1%)
18	150	2 (1%)
19	150	9 (6%)
20	175	10 (6%)
21	200	unknown
22	300	18 (6%)
23	322	8 (2%)

Obviously, all eligible users will not be interested in Talking Books. Respondents' estimates of the proportion of eligible residents who would actually use Talking Books ranged from 1% to 95%, with considerable variation between these two distant extremes. Thus it is not possible to come up with a strong indicator of the likely demand among the institutional population. However, it is safe to assume that those elderly persons in long term care who have been readers throughout their lives will generally want to continue. A recent study (Urban Dimensions Group, 1981) found that 61% of the respondents to a random sample survey had read a book within the past month. Looking at the data in this light, it is clear that there is probably a great deal of unserved demand within the long term care institutions.

9.5 REPORTED NEEDS FOR LIBRARY MATERIALS AND SERVICES AT THE LONG TERM CARE INSTITUTIONS

There is an apparent contradiction in the responses from the institutions. On one hand, almost 75% of the respondents (17 institutions) said that the statement, "Most people here who are interested in reading are already doing it as much as they would like" described reading at their institution better than the statement, "Most people here who are interested in reading are not doing it as much as they would like." On the other hand, 65% (15 institutions) answered "yes" to the question, "If there were appropriate materials and services available to people at your institution, do you think that residents might do more reading?"

Two inferences may be drawn from this apparent contradiction. First, the respondents may have been somewhat ambivalent in answering these two questions because they were not entirely certain what proportion would like to read more than they do, and what proportion do not read at all but might like to. Second, we interpret the majority response--that most people who want to read are doing so as much as they would like--as a sort of caution against expecting that the introduction of better library services would result in a major change in reading patterns for the majority of people.

The fifteen respondents who answered "yes" to the question, "If there were appropriate materials and services available to people in your institution, do you think that residents might do more reading" were asked to indicate the materials and services needed. Table 9.9 shows the responses.

TABLE 9.9
MATERIALS AND SERVICES NEEDED AT
LONG TERM CARE INSTITUTIONS

	Respondents Indicating the Need	
	#	%*
Magnifiers and other technical devices	9	60% (39%)
Materials in languages other than English	8	53% (35%)
Talking Books	7	47% (30%)
People to help the residents with their reading (including volunteer readers)	7	47% (30%)
Large print materials	6	40% (26%)
People to bring the reading materials to the residents	3	20% (13%)

* Percentage is of the 15 respondents who said that residents would do more reading if such materials and services were available. Percentage in parenthesis is of all 23 institutions in the sample.

The two need areas mentioned by more than one-third of all institutions are technical aids and non-English materials. Within the latter category, five institutions specified German and five specified Ukrainian. Cree, Polish, Chinese, and Spanish were each mentioned once.

In their open-ended comments, seven institutions (30% of the sample) noted the need for more large print materials--although two respondents noted that large print volumes are difficult for the patients to hold (implying the need for bookstands). Several respondents voiced complaints about Talking Books service. The criticisms included poor quality among the readers, the need for shorter "action packed" Talking Books (30-40 minutes in length, for people with endurance problems), a poor selection, and slow service. One respondent complained:

ALSH books are very good and our patients look forward to them. However, they are getting very discouraged as service has been so poor and they are without reading materials for several weeks.

Other miscellaneous needs mentioned included large print song books (other than hymnals), more current fiction in large print, more large print periodicals, and more picture books.

APPENDIX A: METHODOLOGY

This study was composed of five related sub-studies:

1. a literature review;
2. in-depth telephone interviews with organizations and agencies involved with disabled persons;
3. focus groups with disabled persons;
4. interviews at major Alberta libraries; and
5. a postal survey to a sample of long term care institutions.

In this Appendix, we document the methods of each of the sub-studies.

A1 LITERATURE REVIEW

Literature was identified through three main sources: the materials available in the offices of ALSH; Rehabilitation Literature, a U.S. periodical published by the U.S. National Easter Seal Society; and a computerized search of the ERIC and LISA databases at the University of Toronto Library. The focus was on materials produced within the last five years. All pertinent sources were read, and some were formally annotated (see Progress Report, August 6, 1982).

The purpose of the literature review was to obtain information concerning the major research questions of the study. First and foremost was the question, "What is a handicap as it relates to library services?" Subsumed in this question are issues of the particular impairments and disabilities which become handicaps when they interface with conventional print formats or the library environment. Another question concerned the numbers of people affected by such handicaps. A third question was levels of use--how many people who experience such handicaps would use library services if they were available? And, finally, what sorts of programs, materials, aids, etc. have been attempted, and how well have they worked to ameliorate or remove handicaps?

The literature provided a great deal of information about the first and fourth questions. Although there were few sources which attempted to explicitly and comprehensively define and describe library service handicaps, numerous articles reported on the difficulties faced by individuals with particular types of disabilities. Similarly, many of the sources described needed programs or services which have been attempted, although few articles systematically

documented the level of use which resulted from special library services.

Appendix B presents a bibliography with brief annotations.

A2 AGENCY SURVEY

There are scores of governmental and voluntary agencies in Alberta representing and/or serving disabled persons. The purpose of the agency survey was to draw upon the knowledge and experience of a sample of these agencies in determining the nature and extent of needs for special library services. Originally, we had intended to conduct a postal survey. However, the research plan was altered to telephone interviews when it came to light that several other surveys involving the agencies were going on at the same time. Because it appeared as if the agencies were being "over-surveyed," we anticipated a low response rate to a postal survey. The telephone survey had the additional advantages of allowing questions in greater depth and of allowing probing for additional information and opinions.

The survey instrument was designed as a semi-structured interview schedule, with most of the questions open-ended. The instrument was somewhat altered depending on whether the agency being interviewed was a province-wide or local organization. The interview schedule is reproduced in Appendix C.

Sampling of agencies was purposive rather than random. The goal of interviewing 50 agencies was not quite met due to a few non-responses (because of summer holidays or lack of success after several call-backs by the interviewer). In all, 41 respondents were interviewed (82% response rate). The agencies were selected to include a cross-section of types of impairments and a variety of locales in the province. The following list shows the agencies which were interviewed.

Calgary Association for the Mentally Handicapped
(one staff and one board member interviewed separately)

Drayton Valley Association for the Developmentally Handicapped

Drumheller Association for Retarded Children

Peace District Society for the Mentally Handicapped

Alberta Association for Children with Learning Disabilities, Drayton Valley Chapter

Camrose and County Association for Children and Adults with Learning Disabilities

Language and Learning Development Association of Edmonton

Alberta Association on Gerontology, Calgary
Alberta Association on Gerontology, Lethbridge
Alberta Council on Aging, Edmonton
Society for the Retired and Semi-Retired, Edmonton
Central Alberta Society for Hearing Impaired
Children, Red Deer
Christian Deaf Centre, Calgary
Society for the Communication Disordered,
Grande Prairie
Society for the Hearing Handicapped, Calgary
Speech Pathology Department, Grande Prairie Health Unit
Alberta Burn Rehabilitation Society
Alberta Children's Hospital, Technical Resources
Library
Alberta Rehabilitation Council for the Disabled,
Grande Prairie
Alberta Stroke Association
Arthritis Society, Alberta Office
Canadian Cystic Fibrosis Foundation
Canadian Diabetes Association, Edmonton
Canadian National Institute for the Blind, Alberta Office
Canadian Paraplegic Association, Calgary Office
Cerebral Palsy Association in Alberta (two interviews--
one with Alberta office in Calgary, one with Edmonton
office)
Epilepsy Association of Calgary
Multiple Sclerosis Society, Alberta Division
Multiple Sclerosis Society, Crowsnest (Blairmore)
Muscular Dystrophy Association of Canada, Calgary Branch

Rehabilitation Society of Calgary
Calgary Action Group of the Disabled
Disabled on the Move
Edmonton Action Group of the Disabled
Grande Cache Association for the Handicapped
Hinton Association for the Handicapped
Medicine Hat Action Group of the Disabled
Red Deer Action Group of the Disabled
Taber Residents for Assistance of the Disabled and Elderly

The quality of information from the interviews varied widely. In a few instances, the respondent had very few substantive comments or suggestions. More frequently, the respondents were thoughtful, specific, and creative in their responses. The overall quality of response was poor only in the area of estimates of prevalence.

Findings from the agency interviews are generally integrated within the text of this report. Appendix D briefly summarizes the overall findings.

A3 FOCUS GROUPS WITH DISABLED PERSONS

Although many of the agency representatives interviewed were disabled themselves, it was important to have a formal mechanism to obtain input from disabled persons. The mechanism used in this study is the focus group.

A focus group is a facilitated group discussion with representatives of a population of interest. The group is presented with a series of issues, and the facilitator attempts to bring the group to consensus on each issue in turn. The discussion is recorded and analyzed for content and tone.

We conducted three focus groups for this study:

1. Persons eligible for Talking Books.
2. Persons who are print handicapped, but in the "gray area" of eligibility for Talking Books.
3. Persons who are not print handicapped, but who have other disabilities which could affect their use of library services.

Participants in the focus groups were obtained through the assistance of various agencies. The Alberta Rehabilitation Council for the Disabled, Southern Region, provided an adapted physical facility for holding the groups.

It was extremely difficult to get participants to attend the discussions, in spite of strong and repeated efforts put forth by both the consultant and the agencies who were contacted. Although an honorarium was offered to pay for transportation and their time, we were unable to obtain commitments from persons representing a few key disability areas (e.g., someone with little use of hands, someone with arthritis). Additionally, some individuals who had made a commitment to attend did not show up. These difficulties run contrary to our past experiences in conducting focus groups concerned with human service issues. The events may be, in part, indicative of the mobility problems faced by disabled persons. However, we have conducted focus groups with disabled persons for other projects without running into these problems in the past. Hence the problems of attendance may reflect a general lack of concern with or an alienation from library services among the disabled population. In order to compensate for the attendance problems, we also interviewed some disabled individuals.

The composition of the focus groups was as follows:

1. Eligible for Talking Books

- three legally blind persons: one congenitally blind, accompanied by a companion; one adventurous (acquired) blindness, no other physical problems; one blind and wheelchair bound due to multiple sclerosis.
- two persons with vision impairments due to diabetes (interviewed separately at Canadian Diabetes Association offices).
- two parents of mentally handicapped adults, with definite organic bases for their inability to read.

2. Print Handicapped but Borderline Eligibility

- one person with multiple sclerosis with intermittent vision problems and not confined to a wheelchair.
- parent of two mentally handicapped offspring (ages 15 and 21) without any diagnosed organic basis for their disabilities.
- parent of learning disabled child without a diagnosed organic basis for the disability (interviewed separately).

3. Not Print Handicapped, Other Disabilities

- profoundly deaf person, accompanied by interpreter.
- hearing impaired person who uses amplification and lipreading.
- person with lower body paralysis (paraplegia) (NB: this person spoke as a representative of physically disabled, mentally alert persons).
- elderly man who has had a stroke; relies heavily on a cane to walk and has some hearing impairment.

Key disability groups not included, either because a commitment could not be obtained or because the individual agreed to participate but then did not attend, were: frail elderly; arthritis; amputee (hands/arms); cerebral palsy; and diabetes without blindness.

The groups were held at the ARCD Southern Region offices on September 8, 15, and 16, 1982. Focus group participants were asked to draw on their personal experiences, but to bear in mind that they were speaking as representatives of their particular disability groups in the province. The agenda used for the discussions is reproduced on the next page. The findings from the focus groups have been integrated in the overall report, but are summarized separately in Appendix E.

A4 INTERVIEWS AT MAJOR PUBLIC LIBRARIES

The purpose of interviews with major public libraries was twofold: to document services to disabled persons, and to draw upon the experiences of the larger libraries for input to the overall study. Interviews were conducted with the director and/or special service librarian at seven major public libraries in Alberta: Calgary, Edmonton, Fort McMurray, Grande Prairie, Lethbridge, Medicine Hat, and Red Deer.

Using a semi-structured interview schedule (reproduced in Appendix F) the interviews focused on the library's services to various disability groups, the respondent's assessment of the utility of those services, and the respondent's assessment of the remaining unserved needs within the community. The interviews were not intended to be evaluative of the library's current services.

The findings of the interviews are presented in Appendix G.

SEPTEMBER 1982

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FOCUS GROUP
"LIBRARY SERVICES TO THE HANDICAPPED"
GROUP MEMBER WORK SHEET

NAME: _____

STEP 1

- A. WHAT ARE THE PROBLEMS YOU HAVE, IF ANY, IN USING CONVENTIONAL MATERIALS FROM LIBRARIES (E.G., BOOKS, MAGAZINES, NEWSPAPERS)?
- B. WHAT ARE THE PROBLEMS, IF ANY, YOU HAVE IN USING A LIBRARY (E.G., GETTING THERE, GETTING AROUND, USING CARD CATALOGUE, COMMUNICATING WITH STAFF)?

STEP 2

WHICH ARE THE TWO MOST IMPORTANT BARRIERS TO YOUR GROUP FROM THE TOTAL GROUP LIST?

STEP 3

WHAT KINDS OF ADAPTATIONS, PROGRAMMES, SERVICES COULD LIBRARIES PROVIDE IN ORDER TO REDUCE OR REMOVE THESE BARRIERS?

A5 INSTITUTION SURVEY

There are over 50 districts in Alberta for purposes of administering long term care institutions. These districts were divided into five size classes based on the number of long term care beds within a district. The size classes were as follows:

1. Less than 100 beds (13.4% of all provincial nursing home and auxiliary hospital beds);
2. 100-200 beds (13.1% of all provincial beds);
3. 330-409 beds (10.3% of all provincial beds;
NB: There are no districts which fall between this class and the previous one);
4. Calgary - 3,290 beds (30.2% of all provincial beds);
and
5. Edmonton - 3,587 beds (32.9% of all provincial beds).

The sampling procedure was to randomly draw five institutions from each size class of district. Because two of the institutions in the sample turned out to be administered together, the sample was reduced from 25 institutions to 24. Twenty-three of the 24 institutions responded to the survey. The respondents account for about one-quarter of all auxiliary hospital and nursing home beds in the province.

The institutions were mailed a questionnaire which is reproduced in Appendix H. The responses were manually tabulated and have been presented previously in Section 9.

APPENDIX B: ANNOTATED BIBLIOGRAPHY

Accessibility checklist 4. The Spokesman, August 29, 1982, p. 29.

This anonymously written article has a brief set of suggested guidelines for making libraries and library materials more accessible. We contacted the Alberta Handicapped Communications Society, which publishes The Spokesman, but were unable to find out the source of the information in this checklist.

Balkema, J.B. Interlibrary cooperation for service to older adults. Drexel Library Quarterly, v. 15, n. 15 (April, 1979): pp. 29-42.

See review in Progress Report to ALSH, August 6, 1982.

Ballard, T.H. More books, not market surveys. American Libraries, v. 12, n. 2 (February, 1981), pp. 76-78.

Although not directly related to services to the disabled, this article has important implications. Ballard persuasively argues that attempts to draw new patrons to libraries are "generally not effective unless there exists a predilection for the product." He suggests that libraries should focus their efforts on the quantity and quality of selection of materials. Using basic principles of marketing, he concludes that libraries should emphasize "closer attention to traditional practices and the importance of a large bookstock." This analysis is congruent with the comments we received from disabled persons and related agencies--that selection is a paramount consideration in determining whether or not to become a patron of special library services.

Berkowitz, M., Hiatt, L.G., de Toledo, P., Shapiro, J., and Lurie, M. A survey to determine the extent of the eligible user population not currently being served nor aware of the programs of the Library of Congress, National Library Service for the Blind and Physically Handicapped. 5 vols. Prepared for the National Library Service. New York: American Foundation for the Blind, 1979.

See review in Progress Report to ALSH, August 6, 1982.

Burns, L. and Reese, P.L. The talking library. Catholic Library World, November, 1980: pp. 164-166.

See review in Progress Report to ALSH, August 6, 1982.

Canadian Library Association Interdisciplinary Committee on Library Services for the Print Handicapped. Library and book needs of the print handicapped in Canada. Submission to the Government of Canada Special Committee on the Disabled and Handicapped. 1980.

The submission recommends "establishment of an adequate program at the National Library for the visually and physically handicapped"

for purposes of coordination; revision of Section 19.1 of the Copyright Act to "facilitate the granting of copyright permissions"; and "a study of architectural barriers...and to create a national building code which will eliminate these and all other barriers to the disabled."

Committee for the Extension of Library Service to Handicapped Albertans. Library service to the handicapped. March, 1976.

This brief proposed a plan for Talking Books services. Of greatest interest to this study is the estimate (in 1976) that there were a minimum of 6,000 to 7,000 Albertans who need Talking Books. Unfortunately, the brief does not indicate how the estimate was arrived at.

Cylke, F.C. Working group of libraries for the blind. IFLA Journal 4 (1978): pp. 256-260.

See review in Progress Report to ALSH, August 6, 1982.

Davis, E. and Davis, C. Mainstreaming library service for disabled people. Metuchen, N.J. and London: The Scarecrow Press, Inc., 1980.

See review in Progress Report to ALSH, August 6, 1982.

A different approach: how libraries can serve the disabled. Metro Toronto Library Bulletin, May, 1981: p. 3.

This brief newsletter article emphasizing adapting regular library services rather than instituting special ones suggests the following adaptive devices: Kurzweil Reading Machine, Visual Ear, Visualtek, magnifying lenses and lamps, and talking books.

Esteves, R. Video opens libraries to the deaf. American Libraries, v. 13, n. 1 (January, 1982): pp. 36, 38.

This brief article mentions various video equipment and materials which could benefit deaf patrons. Some of the suggestions include lending closed caption decoders (for home television viewing), televisions with closed caption decoders for use in the library, captioned foreign films, and video tapes in sign language. The article lists sources of materials and equipment.

Fischer, M.W. The needs of older adults: materials and access. Drexel Library Quarterly, v. 15, n. 2 (April, 1979): pp. 20-28.

See review in Progress Report to ALSH, August 6, 1982.

Gaddes, W.H. Learning disabilities and brain function: a neuropsychological approach. New York: Springer-Verlag, 1980.

The physiological basis of learning difficulties is examined, including a thorough review of current knowledge and controversy in this area. The author also presents discussions of various therapies

which have been tried, and their relative success.

Hagemeyer, A. Library service to the deaf and outreach programs for the deaf (unpublished and undated article).

See review in Progress Report to ALSH, August 6, 1982.

Hagle, A.D. Postal regulations and custom law. In Library service to the blind and physically handicapped: an international approach (F.C. Cylke, ed.). IFLA Publication n. 16. Munich, 1970: pp. 39-74.

See review in Progress Report to ALSH, August 6, 1982.

Hébert, F. Public library service for the handicapped. Ontario Library Review, December, 1977, pp. 266-273.

See review in Progress Report to ALSH, August 6, 1982.

Hébert, F. Copyright and library services for the blind. In Library service to the blind and physically handicapped: an international approach (F.C. Cylke, ed.). IFLA Publication n. 16. Munich, 1979: pp. 39-74.

See review in Progress Report to ALSH, August 6, 1982.

Hébert, F. A new image for Canadian National Institute for the Blind Library. Ontario Library Review, December, 1979, pp. 283-288.

See review in Progress Report to ALSH, August 6, 1982.

Heie, B. Literature and library services for the handicapped in Norway. Scandinavian Public Library Quarterly, v. 3-4 (1976): pp. 92-97.

See review in Progress Report to ALSH, August 6, 1982.

Henley, J. Survey results on library services to the visually and physically handicapped population of Saskatchewan in 1980. Regina: Provincial Library, Development Branch, 1980.

The purpose of this study was to identify existing public library services to the disabled and pinpoint major problem areas. Data was gathered by surveying public libraries, regional libraries, and institutions and agencies serving disabled persons. Response rates to the surveys were relatively high (generally over 50%), but respondents frequently found the questionnaires difficult, and returned incomplete instruments. Findings included: difficulty in estimating the number of people in the target population (estimates ranged from 12,000 to 100,000 in Saskatchewan); critical shortages of staff, funds, and materials; a perceived lack of interest within the disabled population; inaccessible buildings; and communication problems with disabled patrons.

Holvey, D.N. and Talbott, J.H., eds. The Merck manual of diagnosis and therapy, twelfth edition. Rahway, N.J.: Merck Sharp & Dohme

Research Laboratories, 1972.

This physician's manual was used in the study of library services for accurate information about the functional consequences of various medical conditions.

Klauber, J. The partially sighted: low vision and the library. The Bookmark, Fall, 1981: pp. 40-44.

Klauber notes that individuals with low vision (defined as "reduced central activity or visual field loss which even with the best optical correction provided by regular lenses still results in a visual impairment from a performance standpoint") outnumber blind and severely visually impaired persons, but generally do not receive special library services. She recommends large print materials, reading stands, reading and writing guides, and high intensity lamps.

Kraus, K. and Biscoe, E., eds. Summary of proceedings of a symposium on educating librarians and information scientists to provide information and library services to blind and physically handicapped individuals. San Francisco, July 2-4, 1981.

This symposium focused on the education of librarians, and concluded with recommendations to the IFLA concerning curriculum in librarian training programs, accreditation of specialists, international information exchange, and further study regarding specific aspects of librarian education.

Ledwell, Sister J.A. Libraries, librarians, and disabled persons: helping or handicapping? Ontario Library Review, March, 1981, pp. 28-31.

Sister Ledwell addresses the underlying philosophical issues involved in providing library services to disabled persons. Her basic premise is that "free, tax-supported public libraries have long subscribed to the philosophy of 'free service for all,' and have been legislated for and funded on that basis." Hence, she argues, development of library service for disabled persons is a necessary part of the mandate of public libraries.

Library service to those in Alberta unable to read conventional print. Undated, unsigned brief (inferred date: 1974).

This brief argues for a need for provincially initiated and supported services for people who are unable to read conventional print. It includes a short review of some of the special programs which have been undertaken in the U.S. and proposes a five year program, beginning in 1975, "to bring high-quality library service to all visually and physically handicapped Albertans."

Luck, C. Information and referral services for older adults. Drexel Library Quarterly, v. 15, n. 2 (April, 1979), pp. 60-70.

Because of various physical and social limitations, Luck argues that

elderly persons have an especially great need for information and referral services from libraries. She suggests that libraries develop information and referral systems geared for the elderly population.

Mielke, L. New library services for older adults. Catholic Library World, v. 54, n. 4 (November, 1980), pp. 172-174.

Mielke begins by quoting the U.S. National Council on Aging, which states that "Nearly a third of the nation's total elderly population is now comprised of...older persons with physical, visual, speech and hearing and mental impairments." In order to serve this impaired elderly population, Mielke suggests first educating staff to be sensitive to and aware of the needs. Additionally, she suggests special programming (e.g., bibliotherapy); involving older adults in planning special programs; communication with relevant agencies; publicity; and integration of special services into existing service channels.

Newberry, W.F. The last unserved. American Libraries, v. 11, n. 4 (April, 1980), pp. 218-220.

A pilot project offered to residents of an institution for the mentally retarded is described. The article describes the various types of behaviors observed and identifies passivity as a major negative factor. The author suggests that public librarians should visit institutional libraries in order to learn about serving mentally handicapped patrons.

Robinson, W. Meeting the psychological and social needs of older adults: the library's role. Drexel Library Quarterly, v. 15, n. 2 (April, 1979), pp. 5-19.

Robinson suggests that public libraries can play an important role in reducing social problems associated with aging by emphasizing "purposeful activities" as opposed to merely recreational ones. For instance, she suggests that retired persons be used as volunteers for shut-in services; that they collect oral histories, annotate books, and develop discussion groups including younger people also. Underlying Robinson's suggestions is the premise that the library can and should be an instrument of social change, helping to integrate elderly persons into the larger society.

Shumaker, D. International standards for cataloguing materials for the blind and handicapped. In Library service to the blind and physically handicapped: an international approach (F.C. Cylke, ed.). IFLA Publication n. 16. Munich, 1979: pp. 39-74.

See review in Progress Report to ALSH, August 6, 1982.

Standards for Library Service to the Blind and Physically Handicapped Subcommittee of the American Library Association. Standards of service for the Library of Congress network of libraries for the blind and physically handicapped. Chicago: ALA, 1979.

See review in Progress Report to ALSH, August 6, 1982.

Swindley, R. and Kidd, B. Library Services for Disabled People. A Report to the Nation. Melbourne: Australian Library Promotion Council, 1981.

This report examines the needs of the print handicapped population (estimated at 15 persons per 1,000 population), the history of special library services, existing services, needs for materials and services, and needs for physical access. The report rests on the basic premise that disabled persons have a right to "a level of library service not lower than that enjoyed by the remainder of the community" (p. 3). The systemic focus is on development of a nationally coordinated library service to disabled persons. Blind readers, the study found, have been the best served of any disabled group, but "even so, the largest collection of braille books in the country...contains only some 6,000 titles" (p. 11). One of the largest need areas noted by the authors is to "sensitize" librarians to the library service requirements of disabled persons. Other need areas include developing a national clearinghouse on technical innovations, promoting existing services, eliminating duplication of effort in production of materials, allowing users and local librarians to determine the titles to be produced, and revising copyright law so that any title can be produced in special formats.

Thiele, P.E. Formats in non-print media for the blind and visually handicapped. In Library service for the blind and physically handicapped: an international approach (F.C. Cylke, ed.). IFLA Publication n. 16. Munich, 1979: pp. 11-28.

See review in Progress Report to ALSH, August 6, 1982.

Urban Dimensions Group Inc. Project progress: a study of Canadian public libraries. Ottawa: Canadian Library Association, 1981.

Most of Project Progress is only tangentially related to this report. However, the chapter titled "Canadian Libraries and the Public" provides recent survey data concerning reading and library use among the general public. This information is an important context for considering potential reading and library use among disabled populations.

Velleman, R. Serving physically disabled people. New York: R.R. Bowker Company, 1979.

See review in Progress Report to ALSH, August 6, 1982.

Warner-Eddison Associates. Study of the talking book program in Massachusetts. Lexington, Mass.: Massachusetts Commission for the Blind, 1977.

See review in Progress Report to ALSH, August 6, 1982.

Webb, B. Gray and growing: programming with older adults. Drexel Library Quarterly, v. 15, n. 2 (April, 1979): pp. 43-59.

See review in Progress Report to ALSH, August 6, 1982.

Weinberg, B. The Kurzweil machine: half a miracle. American Libraries, v. 7, n. 10 (November, 1980): pp. 603-04, 627.

Weinberg documents the experience of the New York Public Library's mid-Manhattan branch in installing a Kurzweil Reading Machine (KRM). Important points include:

- The KRM is used regularly by a small number of patrons, generally professionals and university students.
- The KRM requires in-depth training of the disabled user.
- Installation of a KRM "requires a labor-intensive effort" on the part of librarians. In addition to training, the user requires in-depth bibliographic work from the librarian.

World Health Organization. International classification of impairments, disabilities, and handicaps; a manual of classification relating to the consequences of disease. Geneva: WHO, 1980.

The conceptual framework for looking at impairments, disabilities, and handicaps presented in this manual is rapidly gaining worldwide acceptance and use. Although the specific classification schemes, which take up the bulk of the manual, are relevant mainly to health care professionals, the introductory sections (albeit difficult reading) are of utmost importance to anyone developing policy or programs to ameliorate the consequences of disease. The basic conceptual framework of the manual was implicitly used to develop the conceptual framework for this study of library services.

APPENDIX C: AGENCY SURVEY INTERVIEW SCHEDULE

INTRODUCTION:

Hello. This is _____ of The Levy-Coughlin Partnership. We are doing a study for Alberta Library Services for the Handicapped, and we'd like to take about ten to fifteen minutes of your time as part of our study.

If respondent is too busy, ask when you could phone back.

If respondent indicates interest:

Our study is an attempt to determine the needs for adapted library services among physically disabled persons, persons with mental impairments or persons with learning disabilities. There are two main things we are trying to find out: first, what kinds of adaptations and special services are needed; and second, how many people need them. We are contacting about fifty organizations such as yours in Alberta as one way of trying to get this information.

If respondent is too busy, arrange an interview time.

Before I ask you our specific questions, I should give you some idea of the way we are conceptualizing what we call library service handicaps. In general terms, we see two main ways that a person may be handicapped in relation to library services. First, a person may be handicapped because of a functional disability that prevents reading printed materials in their usual formats. This kind of handicap can result when the person has trouble seeing, or holding books, or turning pages, or having endurance, or this handicap may result from cognition or comprehension difficulties with conventionally available materials (such as someone who is mentally handicapped, or deaf and cannot read written language).

Second, a person may be handicapped with regard to the library environment itself. These handicaps can be physical--there may be problems with architectural barriers such as stairs, or signs or fixtures such as high tables or card catalogues, or they may, because of their situation not even be able to get to the library. Or, there may be problems with the human environment, meaning they may not be able to use the established channels of communication like making written requests, reading signs or leaflets, or simply communicating with the library staff.

Don't be too concerned about restricting your comments to a particular category, or not confusing the categories. I just wanted to point out that we are approaching the question in broad terms and that there are many aspects of library services that might be potentially handicapping for some individuals.

1. In what ways might (an individual with _____)
(disabled individuals in Alberta)* face barriers because
of difficulties in dealing with public library materials
such as books, magazines and newspapers?
2. What kinds of adaptations, programs, or services might
public libraries provide in order to reduce or remove
these barriers?
3. In what ways might (an individual with _____)
(disabled individuals in Alberta) face barriers in actu-
ally getting to and using the library premises as used
by the general public?
4. What kinds of adaptations, programs, or services might
public libraries provide in order to reduce or remove
these barriers?
5. [If respondent has indicated no problems or barriers.]
Are there any aspects of public library services whatso-
ever which can put people with _____ at a disadvan-
tage relative to the general public? [If nothing, thank
and terminate interview.]
6. Do you think that the barriers to using libraries and
their materials are different depending on whether the
person lives in a city, a small town, or a rural area?
7. What advantages, if any, would (individuals with _____)
(disabled individuals in Alberta) gain in their daily lives
if the barriers to using conventional library services were
dropped?
8. In terms of priorities for public libraries, which aspect
of libraries do you think is most important to improve
first for (people with _____) (disabled people in
Alberta)?
 - Recreational--primarily for pleasure.
 - General informational--may be for pleasure, but with
the added dimension of seeking
information. Includes news,
general knowledge.
 - Specific reference--when a person requires some specific,
predetermined information, requiring
some research technique to be able
to obtain.

* Words and phrases in parentheses indicate the variations in
wording that were used depending on the type and scope of the
agency being interviewed.

9. How important would you rate improvements in library services for people with _____, as compared with improvements in other special service areas for the disabled? [Response choices: very high priority, fairly high, medium, fairly low, very low.]

[NB: Questions 10-15 will not apply to all agencies. These questions will be most often answerable by province-wide organizations which deal with a specific impairment.]

Now, I'm going to ask some questions that will help us estimate the number of people who might use and benefit from adaptations, special programs, and services. Please, when I ask you about estimates of number, just do your best to provide rough estimates. We realize that there is little accurate data about prevalence.

10. (a) How many Albertans do you estimate have _____?
- (b) We are eliminating children ages five years and younger from our study, so please estimate the number of children ages five and younger with _____.
11. What proportions of Albertans with _____ are living in institutions?
12. What are the differences in prevalence, if any, by age and sex?
13. Does the distribution of people with _____ mirror the general distribution of population in Alberta, or is the condition more prevalent in some areas? Where?
14. (a) How often does _____ occur as part of a multiple disability? What are the most common associations?
- (b) What complications can occur as a result of _____? How often do these complications occur?
15. What proportion of people with _____ might experience a handicap with relation to:
- Reading?
 - Holding books, sitting, turning pages?
 - Maintaining stamina necessary for reading?
 - Cognition and comprehension of materials?
 - Physical access--getting to the library, moving freely within the library, using the fixtures?
 - Communications, written or verbal?

- Tolerance to the environment--varying levels of light, noise, temperature, dust; or be able to manage without non-transportable aids?

16. [For local organizations only.] How many people in your area do you estimate have _____?
17. Is there anyone else in Alberta who you suggest we talk to?
18. Is there anything else you would like to add?

APPENDIX D: SUMMARY OF AGENCY INTERVIEWS

This appendix summarizes the input gained from agencies serving disabled persons. The summary excludes agency input regarding prevalence of disabilities, because the quantity of information was small and the quality of information was poor.

MATERIALS

Agency representatives mentioned Talking Books and large print materials as the greatest need. With regard to Talking Books, most often respondents expressed a desire to have them made more easily accessible, and for the eligibility criteria to be more widely known and easier to understand. Another frequent comment was that the Talking Books selection needs to be improved, both in terms of quantity and in terms of the kinds of materials in special formats. The suggestion for having high interest/low vocabulary Talking Books and large print materials was quite common. Agencies involved with the elderly expressed a need for shorter Talking Books, because of endurance problems among some of the frail elderly population. With regard to large print books, respondents generally felt there are not enough of them available, and that they are often dated by the time that they are available.

There were very few requests for increased availability of audio-visual materials as alternatives to traditional print format materials. However, several respondents suggested that there should be Talking Books available with accompanying illustrated texts. This particular suggestion was made by a variety of groups.

In terms of technical aids, respondents most frequently expressed a need for simple items such as magnifying devices, high intensity lamps, book stands, and page turners. No one expected to see libraries install costly high technology equipment. Several key sources who were knowledgeable about technical aids expressed a real skepticism about the usefulness of making such "as yet unproven and unperfected equipment" available even in the major centres. Instead, respondents tended to suggest simple things such as making both hardback and paperback editions of materials available so that individuals could opt for whichever was easier to handle.

Organizations which deal with individuals with hearing impairments, learning disabilities, and mental retardation, as well as organizations dealing with the elderly often expressed a need for materials with a high pictorial content. In particular, two organizations dealing with deaf and hearing impaired persons suggested that there be conventional books accompanied by a text in sign language. Organizations which serve physically disabled persons suggested

materials which are easier to handle (e.g., spiral binding) and more durable (e.g., plastic coatings).

LIBRARY ENVIRONMENT

By far the greatest interest in answering questions was shown during this portion of the interview. In fact, many of the respondents tended to ignore or gloss over the questions relating to materials in their eagerness to answer the questions related to the library environment.

Most respondents mentioned architectural barriers as a potential problem. Agency representatives stressed the danger of making incomplete architectural adaptations (e.g., building a wheelchair ramp which leads to a revolving door).

Transportation problems also were mentioned frequently, in connection with almost every disability group. In particular, respondents often pointed to a lack of good parking facilities adjacent to a library, a consideration which is more necessary to disabled and elderly populations than it is to the general public. Similarly, the lack of good public transportation to a library was noted as a major barrier to library use among the disabled and the frail elderly populations.

One of the most universal comments encountered in the interviews related to difficulty in dealing with library systems. There seemed to be a consensus among the respondents that locating materials (i.e., generally figuring out how to get what you want) is the most intimidating aspect of libraries for disabled persons. Many have never been exposed to library use before and are absolutely lost. Respondents suggested that libraries take a twofold approach to handling this problem. First, workshops designed to explain the "mysterious" how-to's of functioning in that environment would be a key to helping disabled persons feel comfortable in a library setting. This understanding was seen as a prerequisite to gaining and strengthening independence by enjoying full use of a public facility. Second, a widespread desire was expressed for simplified information and coding systems. Respondents suggested that informational pamphlets on locating materials should be made available in clear, large print, basic language. Along with conventional methods of indicating the location of a book (both in the catalogue and on the shelves), respondents suggested pictorial symbols, colour coding, and other simplified locational systems. For example, high interest/low vocabulary books could be marked by blue dots on the spine, blue marks on the shelves, and could be filed in a blue cardex box.

More important than any other single issue was the need for understanding on the part of library staff.* Often, a respondent would list a number of technical aids or special programs which they would like to see available, and then say something such as "...but you wouldn't really need all that if there was someone there who knew how to deal with the disability and had the time to spare." This is not to suggest that staff should serve where devices like page turners will help to give a person more independence. However, costly adaptations and materials might be foregone if there were staff who were willing and able to assist personally. Although the survey respondents were full of suggestions for changes to be made to libraries, they seemed to be acutely aware of the fact that budgets are limited and renovations are costly. The human aspect of the environment appeared more important to the respondents than the physical aspects of the library environment. Agencies representing "invisible disabilities" (e.g., communications problems and problems associated with aging) felt especially misunderstood. These impairments have been apparently mistaken too often for stupidity, and many respondents felt that public librarians should be helping to inform the public on these matters rather than perpetuating misunderstanding. There was complete agreement that every library should train its staff in identification and understanding of specific disabilities. In a similar vein, respondents believed that libraries should make an effort to develop and maintain extensive collections of materials about various disabilities, and that these collections should include materials which address the issues at various levels, so that children, mentally retarded adults, and other groups could read about their own impairments and develop better understanding.

URBAN/RURAL, CENTRALIZED/DECENTRALIZED LIBRARIES

Most respondents believed that while the resources of a small library may be limited, and the physical access may also be limited, there are fewer attitudinal barriers in smaller towns, rural areas, and small libraries. The agency representatives believed that people would be more willing to help in a smaller library, and that the smaller size of the building and the library collection would be much less intimidating than in a large public library. While

* The interviewer for this segment of the project wrote, "At the risk of being facile, I think I can honestly argue that agencies would be willing to give up on the idea of special services and materials if they thought they could count on the cooperation and sensitivity of library staff. As far as I could see, the disabled population feels it can count on being misunderstood, misinterpreted, patronized, and not much more. (Please note, there were several communities in which respondents said that their librarians were excellent and very accommodating, so this remark does not apply specifically to every community in Alberta.)"

respondents noted that physical access tends to be better in a large library in a major urban centre, they believed that the city has a "rat race" element that is particularly difficult for some disabled persons. They believed that the sheer size of a large public library was very intimidating and that staff were often too busy to assist or explain library systems.

BENEFITS OF LIBRARY SERVICES TO DISABLED PERSONS

Agencies stressed the sense of normalcy that using libraries could promote among their clients. Several respondents are concerned about the many barriers which disabled persons face to recreational activities, and believe that improved library services can help to meet a real need for recreation. As well, many groups stressed the sense of inclusion and integration into the community that using public libraries could promote.

CONTENT OF SPECIAL MATERIALS

In the agency interviews, we asked the respondents to state which content areas were most important to improve first. Special materials for recreational reading and general information were mentioned most frequently. In comparison with these areas, specific reference materials and services were given a low priority. News and public affairs information came up frequently as areas of particular interest.

LIBRARY SERVICES AS A PRIORITY FOR DISABLED PERSONS

Respondents were asked to rate improvements in library services in terms of their importance in relation to improvements in other special service areas for the disabled. Respondents were split between high priority and low priority. However, this split may be slightly misleading. Respondents tended to answer in one of two ways. Either they indicated that improvements in library services were a high priority "philosophically speaking," or they indicated that library service improvements were a low priority "realistically speaking." When respondents said that library service improvements were a low priority, they noted that it was not because they thought that library services are a frill, but rather that they are a priority that unfortunately needs to take a back seat to more pressing priorities such as adapted housing and transportation. Nonetheless, many respondents seemed to believe that library services are the type of public services which can really promote integration and normalization among the disabled population.

APPENDIX E: SUMMARY OF FOCUS GROUP FINDINGS

GENERAL COMMENTS

- Some people (e.g., elderly stroke victim, partially blind people, and blind man) either had little opinion about library services or had given up reading and libraries as too difficult, and relied on other information sources (e.g., friends, radio).
- Most who came had strong ideas of their service needs and ways to change existing situation.
- Groups were identified which probably would not make major use of libraries in the short run, even if services changed: the deaf (past history, illiteracy); adult mentally handicapped (no history of going); stroke patients; young learning disabled (school libraries adequate). Nevertheless, the groups felt suggestions for changes would make some impact (albeit at a slow rate) and should be implemented.
- Commonalities were difficult to identify, both within and across groups. Each disability and, indeed, each individual problem is often unique. This points to the difficulty of providing services to meet a great diversity of needs.
- The question arose of centralized services versus services at branches. Most felt that a concentration of centralized services in a city is not desirable given parking problems, but recognized the expense of duplication to branches. The participants suggested that any expensive technical aids (e.g., reading rooms, video-tape machine) be centralized for a trial period to see if they are well used.
- The "borderline eligible" group felt libraries could charge a small fee for rental of VTR, cassettes, and any other expensive equipment to offset costs.
- Some positive experiences were reported:
 - people found much of staff helpful, kind.
 - appreciated delivery service to their home or local branch library
 - found longer permitted borrowing time useful (fatigue means they read slower)
- The eligibility criteria for Talking Books are not widely known and not understood, even by associations that are set up to help people with disabilities. One person described the lengthy

process a local agency went through to find out the criteria.

- Eligibility often depends on an ophthalmologist's interpretation. Many seem unwilling to register people until they are legally blind. There is a great variation between physicians in general.
- Several expressed criticisms about Talking Books service (delay in delivery, limited range of titles).

SPECIFIC ISSUES

1. What are the problems you have, if any, in using conventional materials from libraries (e.g., books, magazines, newspapers)?

<u>Concern</u>	<u>Group</u>		
	<u>Eligible</u>	<u>Perhaps</u>	<u>Ineligible</u>
Content and types of books age inappropriate	X	X	X
Can't see to read	X	X	
Difficulty in obtaining textbooks on tape	X		
Page turning			X
Need assistance with forms, photocopiers	X		
Need assistance doing literature search for business or research purposes	X		
Difficulty in finding readers	X		
Illiterate (dyslexic)		X	

COMMENTS

All Groups

- Types of books: range too narrow; too much fiction; not enough high interest/low vocabulary books.
- Choice of large print and low vocabulary books and Talking Books is currently so narrow that it stops many from using library; either know there is nothing age appropriate (mentally handicapped) or that has not already been read (blind).
- Totally blind: can't see and therefore need to use braille or Talking Books.

- Partially sighted may be eligible or ineligible depending on physician's interpretation. Fluctuating vision (multiple sclerosis) makes reading fatiguing or difficult and therefore need large print or Talking Books.
- Talking Books could help mentally handicapped to learn to read (parent reported that's how her mentally handicapped son learned).
- Partially sighted: problem using regular textbooks--needs them on tape or read to by someone and it is difficult to get readers; difficulty in using photocopier and forms.

Perhaps Eligible

- Reading very fatiguing as vision fluctuates with multiple sclerosis--Talking Books would be of benefit.
- Some learning disabled are dyslexic and can't read any printed material, or else have great difficulty.

Ineligible

- Page turning and reaching books are problems.

Staff Assistance

- Staff helpful but often too busy.
- Must give two days' notice to do photocopying (blind woman).
- Both blind and physically handicapped felt they were imposing on staff if asked them to do a search for books for a specific purpose (e.g., term paper) which took more than 15 minutes. To do an adequate job could easily take two to three hours.
- Blind woman: "The biggest problem is the limited material. You are always at the mercy of what people think you are or should be interested in."

2. What are the problems you have, if any, in using a library (e.g., getting there, getting around, using card catalogues and other information sources, and communicating with library staff)?

<u>Concern</u>	<u>Group</u>		
	<u>Eligible</u>	<u>Perhaps</u>	<u>Ineligible</u>
Architectural barriers outside buildings, e.g., curbs, ramps	X	X	X
Lack of parking	X	X	X
Distance from parking or bus	X		X
Barriers within library, e.g., washrooms, fountains	X		X
Lack of braille on elevators, phone in library, floor covering (hard for wheelchair)	X		X
Library size and layout (crowded)	X		
Card catalogue and fiche	X	X	X
Insensitive staff			X

COMMENTS

Access

- Accessibility a problem for all groups.
- Discussion focussed on Calgary: parking identified as a problem in branches, where there may be none or without ramps; and downtown, where it is too far away for people to manage, fatigue a problem.
- Branches especially faulted for lack of washrooms, let alone accessible ones.
- Need for braille on elevators, phones.
- Parking: need room for wheelchair van.

Layout

- A problem to wheelchair bound who couldn't manoeuver and mentally handicapped who found it confusing.
- Parents have had to gather books into one area or take out for their adult child, which creates further dependency.

Catalogue and Fiche

- A problem for all groups; "a mystery" to the deaf.
 - technical terms not understood so can't use efficiently
 - difficulty in reading
 - easily tire from reading
 - physically handicapped can't use catalogue

Location of Materials

- A problem for physically handicapped--shelves too high; can't see record jackets clearly.

Insensitive Staff

- A problem identified by deaf and hard of hearing, both of whom have been mistaken for being drunk or been asked why they are relying on paper and pencil; feel staff education and more disabled people in library a way to overcome this: "Staff must understand right of non or minimal reader to use library."

3. What kinds of adaptations, programs, services might public libraries provide in order to reduce or remove these barriers?

	Group		
	<u>Eligible</u>	<u>Perhaps</u>	<u>Ineligible</u>
Wider choice of books--non-fiction, high interest/low vocabulary books	X	X	X
Expand number and types of records	X	X	
Expand number of large print books		X	
In service training for librarians on disabilities and special needs	X		X
Coordination with other services, e.g., CNIB, NFB, N.Y. Reading for the Blind, university libraries	X	X	X
Publicity about existing services and eligibility for Talking Books (in forms blind can use)	X	X	X

	Group		
	<u>Eligible</u>	<u>Perhaps</u>	<u>Ineligible</u>
Public education on library services and use of catalogues/fiches	X	X	
Store information about disabilities	X	X	
Special service library staff	X		X
Develop volunteers to do literature search, be readers	X		
Expand telephone information services	X		
Provide more stools		X	
Develop cable television--read books on air	X		X
Video cassettes: captioned	X		
Technical aids, e.g., page turner, room for reading	X		X

COMMENTS

Minor Costs and Ease of Implementation

- More stools available for reaching books and for sitting on (fatigue a problem).
- More long reachers available for reaching from wheelchair.
- More staff education about disabilities: could be done by organizations with no cost to libraries.
- Weed out existing books on disabilities to watch for negative stereotypes, e.g., "idiot" for mentally handicapped, or outdated advice.
- Store various associations/self-help groups/associations newsletters to provide information to general public about disabilities and resources: "A large proportion of people with handicaps are unaffiliated" and therefore out of these networks.
- More staff education about Talking Books criteria and CNIB services.
- More staff doing public information about existing library services and how to use catalogues (e.g., presentation to deaf club meetings).

- Coordination and publicity about existing services (all groups), e.g., TTY service not well known; list of books currently in large print and in Talking Books (in form blind can use, ideally).
- Centralized catalogue of resources and services.
- Better coordination with other agencies; avoid duplication, make resources better distributed.
- Set up textbook exchange and listing of locations of texts on tape (very difficult to have taped or brailled--would be of benefit to students and avoid duplication--currently very limited in choice of available materials for courses and supplemental reading).

Major Costs

- Book selection
 - expand number of Talking Books and large print materials
 - expand number of high interest/low vocabulary books and widen area to include books on sports, humour, cookbooks, and do-it-yourself (would help increase independence in community for all, especially mentally handicapped)
 - expand range of Talking Books--suggestions included:
 - more nonfiction, including news magazines (important information source for deaf); National Geographic
 - legal information, e.g., AISH, tenant's rights, AID book
 - information for teenagers on illegal drugs/sex education
 - information on disabilities/technical aids/medical advances
 - do-it-yourself books, e.g., teach to type, cookbooks
 - biographies
 - historical novels
 - reference texts
 - classics
- Record selection
 - expand number of titles and types
 - increase number available with books (now available commercially)

- Special service librarian
 - attuned to needs of disabled library patrons
 - could assist in catalogue use and book location
 - would mean patrons wouldn't have to "wait and hope someone would offer service"
 - could do staff education among librarians (perhaps coordinate services with others?)
 - more important than spending money on fancy technical items (e.g., Kurzweiler very tempermental, requires lots of training to use)
- Have braille books available in public library: "Why (blind woman asks) is it necessary to go through Toronto (CNIB)?"
- Telephone information services: expand to make it easier for people for whom transportation to main library is difficult.
- Set up volunteer corps to provide special services (e.g., from senior citizen centres)
 - volunteers to be used as readers for taping (source: drama departments, universities, colleges)
- Architectural changes
 - provide ramps, etc. (see Question 2, above)
 - provide soundproof areas where readers could read aloud to blind without disturbing others in library
- Technical aids
 - provide page turner and magnifiers to branches
 - provide video cassettes with captions added
 - provide VTR machine in large libraries where tapes could be shown (perhaps on experimental basis)
 - provide four-track tape on Talking Books--makes chapter scanning easier for blind
 - provide four-track tape machines for people to listen to tapes on
- Libraries to link up with public television (cables) and read books over air; closed caption to make it accessible for hearing handicapped too.

4. Do you think the problem areas would be different in rural areas and small towns? How?

COMMENTS

- Generally all felt problems would be more difficult in rural area, e.g., transportation would be more of a problem; also accessibility.
 - One lady who had lived in northern Alberta stated that the hours a library was open was a problem: limited budgets meant limited hours, therefore library often not open in evenings or weekends when disabled people could get to them.
 - One physically handicapped man felt that although rural areas might be more personal, they would foster more dependence.
 - All felt importance of having criteria for Talking Books spelled out and available in rural areas, where other sources of information regarding the program are more limited.
 - Parent of mentally handicapped felt it was of higher priority to expand services in rural areas where there are fewer services and agencies available as resources.
5. How important is it to remove/reduce these barriers, given that funding for special projects is always limited? Compared with other special services for disabled persons, how important are special library services?

COMMENTS

Eligible

- Pointed out that legally blind people have access to Talking Books through CNIB, although there are problems with this service (four to six week delay, titles ordered not sent); felt libraries would be very important for those without access to CNIB.
- Should be very important to mentally handicapped as a legitimate type of recreation (a large need is for satisfying social experiences).

Perhaps Eligible

- Woman with multiple sclerosis: libraries very important to her personally; feels people would use more if knew more of what services are available currently.

- Parents of mentally handicapped children: currently libraries not important and probably would not be for long time for many people--children have stopped using once reach chronological age that normal kids read--can no longer find books that are age appropriate.
- Learning disabled parent: expressed same problem and lack of age appropriate material for those who can read somewhat; said that for severely involved cases or most major needs there is therapy and tutoring "well beyond the role of the library."

Ineligible

- Deaf man and hard of hearing woman: for the deaf probably few will use immediately--will take a long time until people are educated in services available and benefits; for them as individuals, libraries fairly high priority versus need for other services; helps them break out of "isolated shell" their deafness causes and gives them factual knowledge about the world.
- Physically handicapped male: "If it's a public library it should be public"--accessible to all--strong feelings.

GENERAL CONCLUSIONS

1. Major problems for all groups:
 - accessibility to facilities
 - content of Talking Books and lack of availability of high interest/low vocabulary and large print books
2. Major suggestions:
 - not all costly
 - focused on beefing up existing services through
 - better staff education
 - better publicity
 - better coordination between bodies providing specialized library services
 - more use of volunteers
 - not all negative; in fact, Talking Books seen as so useful that all wished expansion of eligibility criteria so more people could take advantage of them

APPENDIX F: INTERVIEW SCHEDULE
FOR MAJOR PUBLIC LIBRARIES

QUESTIONS FOR INTERVIEWS AT MAJOR PUBLIC LIBRARIES: AUGUST, 1982

1. In addition to circulating Talking Books, does the library provide any special services, materials, or technical aids for persons who:

DISABILITY	DESCRIPTION OF SERVICE	ESTIMATED LEVEL OF USE MAJOR AGE GROUPS	OTHER COMMENTS
Are blind			
Are not blind but have difficulty seeing print, even with glasses			
Have physical problems that make it difficult or impossible to handle books (e.g., spastic, missing limbs)			
Have physical problems making it difficult or impossible to sit or maintain other posture for reading			
Have physical problems that limit strength, endurance, easily fatigued			
Have learning disabilities hindering ability to read, though intellect and vocabulary may be normal			
Have brain dysfunction (e.g., mental retardation) keeping reading ability low, along with below average intelligence and vocabulary			
Are unable to get to the library, living at an institution			
Unable to get to the library, living at home			

DISABILITY	DESCRIPTION OF SERVICE	ESTIMATED LEVEL OF USE MAJOR AGE GROUPS	OTHER COMMENTS
Can get to the library but are in a wheelchair			
Use canes, crutches, or a walker			
Cannot take books off shelves			
Cannot see to read information signs, leaflets			
Cannot coordinate use of card catalogues			
Cannot speak or hear over the telephone			
Cannot hear or speak well enough to communicate with the library staff			

2. Does the library carry any braille materials?

no yes (describe) _____

3. How are talking books delivered to patrons? (if more than one way, estimate %)

a. patron comes in, or must send in a family member or friend _____

b. volunteers deliver _____

c. staff deliver _____

d. other _____

4. Does the library provide any special services for talking book patrons who are unable to use the playback machines?

no yes (describe) _____

5. Does the library have any talking books, large print, or braille materials in languages other than English?

no yes--what languages? _____

Would you say that these materials get about the same, less, or more use per volume than special materials in English?

same less more other comments _____

6. For what languages (other than English) would you say that there is the most need for material in special formats? (rank order)

no other languages _____

7. Does the library have a collection of high interest/low vocabulary materials?
no yes (describe) _____

8. Do you think that there is additional need in your community for special library services for people who are:

	No	Yes	Describe
Learning disabled	_____	_____	_____
Mentally retarded	_____	_____	_____
Elderly	_____	_____	_____
Deaf/hearing impaired	_____	_____	_____
Institutionalized	_____	_____	_____
Other:	_____	_____	_____
	_____	_____	_____

9. In terms of age groups, where do you think the needs are greatest in your community (please rank)

_____ children
_____ teenagers
_____ young adults
_____ middle-aged adults
_____ elderly

10. Does the library maintain any special collection of materials about disabilities?
no yes (describe) _____

11. Does the library maintain special files, booklets, etc. about resources in your community specially equipped to assist people with disabilities?
no yes (describe) _____

12. In developing and providing special library services, does the library consult or work with organizations concerned with disabled persons?
no yes (describe) _____

13. In what areas and to what extent does the library use volunteers in providing special services?

does not use volunteers

uses volunteers: _____

14. What would you say are the strengths and weaknesses of using volunteers?

strengths _____

weaknesses _____

15. How has the library publicized its special services?

_____ how effective? _____

_____ how effective? _____

_____ how effective? _____

16. What training has the library done internally to educate its staff about various disabilities?

none

yes (describe; how effective) _____

17. Do you think that there is need for any (additional) training of staff to better understand disabilities and their implications for the library patron? (e.g., so that staff recognize that a person with cerebral palsy may sound drunk or mentally retarded, but actually may be extremely intelligent; how to facilitate and what are the limitations on lipreading)

no yes

comments _____

18. What are the main factors that prevent your library from doing more in the area of special services to people with disabilities?
19. What roles do you think Alberta Library Services to the Handicapped could best play in the future? In what ways could they help facilitate your provision of services to people with disabilities?
20. Do you have any comments, based on your experiences, that you think might be helpful for other public libraries in Alberta to know about?
21. Do you have any other comments related to library services for people with disabilities?

APPENDIX G: FINDINGS OF MAJOR PUBLIC LIBRARY INTERVIEWS

CALGARY PUBLIC LIBRARY

The Calgary Public Library (CPL) provides a broad range of services to disabled patrons, primarily through its Outreach Services. Its experiences, documented in detail below, may provide considerable assistance to other public libraries in the province.

SERVICES TO DISABILITY GROUPS

Blind and visually handicapped patrons. The CPL has 36 playback machines which it will loan to Talking Books patrons for a period of up to three months. The machines are not used by CNIB registrants, but by other visually impaired persons, usually when they begin on the program. This service, which alleviates a burden of financial investment on the patron when he/she begins using Talking Books, may be one of the reasons why such a large proportion of the print limited population has registered for Talking Books in Calgary (see Section 5). On the average, the CPL estimates, 24 of the players are out; at times the library finds that demand exceeds supply.

A recent addition to the Outreach Services is the World Book Encyclopedia on tape, with a specially designed playback machine which allows a user to "flip" to a particular entry in an analagous fashion to finding an entry in the print version. The encyclopedia is being used about once a week, more for general reading than for specific reference.

Outreach Services also has on premises a large print typewriter, which is used about once a week. Because the typewriter and the World Book are fairly new, many patrons do not yet know about them.

The CPL carries about 4,000 titles in large print, with a circulation from the central library alone (excluding branches) of about 20,000 per year. The library sends collections of large print titles to its branches, also. Although the CPL has "just about all the titles available" in large print, demand exceeds supply. The library receives about two dozen requests each month for large print titles which are not available.

Recently the CPL purchased two Visualtek read/write systems. One of the machines has typewriting capabilities and one is portable, allowing the patron to use it in any location within the library. The machines are not receiving as much use as was hoped, but the library recognizes that development of a regular clientele for such

equipment is a slow process. Many patrons still do not know about the Visualteks. The machines are used about once per week.

Smaller devices, such as magnifying lamps, receive greater use (about six patrons per week). The library loans out some of the smaller devices so that patrons can try them out before buying their own.

The CPL has large print and tape recorded listings of the Talking Books selection for people who cannot use a regular catalogue. The library is getting tactile panels for its elevators so that blind and vision impaired patrons can use the elevators without assistance.

Physically disabled patrons (i.e., mobility, coordination, posture, strength, and endurance problems). Outreach Services has one overhead bookstand (to be used when a person is confined to a bed) for display purposes, so that the public becomes aware that such an aid is available. The library also owns several page turners and bookstands to be used in the library, as well as some for loan. About four or five are checked out each month. Outreach Services provides patrons with plans for having their own stand built.

There is a volunteer program to assist Talking Books patrons who are unable to coordinate use of the cassettes and playback machines. The volunteers will deliver the tapes as well as put them in the playback machines. About 40 volunteers serve over 100 Talking Books patrons (most of whom are in institutions) in this way.

The CPL also has a Homebound Readers Service for people unable to read books themselves. About 70 patrons use this service. Patrons are matched with volunteers on a one-to-one basis. The volunteer and the patron determine the frequency and extent of services together. The majority of patrons are elderly. There are also a few with multiple sclerosis, traumatic injuries, and burns. Because of a high mortality rate and a high rate of patrons moving to institutions, the program itself has a high turnover rate.

The CPL runs a delivery service to homebound readers living alone and to institutionalized readers who are not able to get to the library or a branch themselves. Most long term care institutions in the community have deposits delivered to them. The deposits consist mostly of large print materials. Some institutions also have a person who coordinates Talking Books to registered residents.

The washrooms at the CPL are adapted. The Outreach Services department is barrier free for disabled patrons. The shelves are reachable from a wheelchair, aisles are wide, and there are special tables which accommodate a person in a wheelchair. If a wheelchair bound person or a person using canes or crutches is spotted at the library entrance (by the Information Desk staff), the Outreach

department is phoned. Staff then check to see if the patron needs any special assistance.

Deaf and hearing impaired patrons. The CPL has a TTY/TTD system and a TTY directory so that deaf patrons can phone the library for information. Deaf members of the community who do not have their own equipment have also been coming to the library in order to make personal phone calls. The special system is used about twelve times per month. Although deaf patrons typically communicate with staff by writing notes, there is one hearing handicapped staff member who signs.

Additionally, the CPL has some captioned films, mainly directed to children and young adults.

Reading disabled and mentally handicapped patrons. Although the CPL does not have any services specially developed for these patrons, the Social Science and Humanities department maintains a "literacy collection" of about 1,000 titles. There are also deposits in four branches. The collection mainly includes large print, high interest/low vocabulary volumes, and work books. The library is beginning to add photo novels and best sellers to this collection. The staff has noticed extensive use by elderly patrons.

BRAILLE

The CPL carries and does little purchasing of braille material. There are a few children's books as well as some governmental information. The library cites storage problems as a major reason for not maintaining extensive braille holdings.

SERVICES RELATED TO TALKING BOOKS

About 30% of the Talking Books patrons come to the central library, or send a family member or friend, to pick up their selections. This proportion is on the rise. Only about 3% of Talking Books are delivered by volunteers. The remainder are delivered either through the library's own delivery service or through branch libraries. The CPL is trying to encourage patron pick-up at branches because of heavy demands on the delivery service.

In addition to the special services already described, the CPL offers personalized service in training patrons in the use of the playback machines. Delivery staff will sit down with new patrons to teach them to operate the machines. Sometimes the new patron feels that he or she will be unable to learn. However, the CPL has found that with repeated, persistent, patient efforts on the part of delivery staff, most patrons succeed in learning how to use the machines.

MATERIALS IN OTHER LANGUAGES

The CPL carries a few Talking Books in French. These materials receive about the same level of use as English language Talking Books. The library has recently ordered some large print volumes in several European languages. Elderly and institutional populations have frequently requested materials in other languages. Outreach Services ranked demand for special format materials as follows: 1. German; 2. Polish, Ukrainian, and Russian; 3. Chinese; 4. Dutch, Hindi, and French.

USE OF VOLUNTEERS

Outreach Services makes extensive use of volunteers, as has been noted above. There are currently 160 to 165 volunteers, several of whom have been volunteering since 1975, when the program began. The library attributes its low turnover and high level of commitment among volunteers to ongoing personal contact. "You can't just hope it's working," an official told us. "Volunteers need recognition in a personal way." In addition to initial training, the library personally contacts each volunteer at least twice a year; once a year the volunteers receive a newsletter; and each year the library honors its volunteers at a banquet. The library's strong programs for disabled and elderly populations rely heavily on the services of volunteers. However, the volunteer program requires a large staff commitment to maintain at a high level of quality.

STAFF TRAINING

Although the CPL has not done a great deal of special staff training in the area of disabilities, it sees a need for increasing efforts in this area. Outreach Services instructs staff in key places (e.g., Information Desk). Recently the department was called upon to serve at a staff training seminar, for which disabled individuals from the community served as resource people. The remaining special training occurs informally (e.g., when a staff member has questions about assisting a disabled patron). In its training, Outreach Services tries to emphasize the basic humanity and "ordinariness" of disabled persons.

PUBLICITY

Outreach Services publicity has been sporadic because of limitations on time and resources. The Public Relations department has assisted, and posters and brochures have been produced for display in libraries and through agencies (e.g., Meals on Wheels, Multiple Sclerosis Society office). Speaking engagements for fund-raising and media coverage have also helped to publicize the services. Although the

library has found these formal efforts to be very effective, word of mouth is the most important means of publicity.

REMAINING NEEDS FOR SERVICES

The CPL Outreach Services believes that there is additional need in the community for special services, especially for learning disabled and mentally handicapped persons who--under current interpretations of the eligibility criteria--do not qualify for Talking Books yet are unable to read conventional print materials. The library also sees additional needs for educational and high interest/low vocabulary materials for deaf and hearing impaired persons.

In terms of age groups, the library believes that elderly and school-age patrons are being well served with special materials and services. The greatest unmet need is in the 18-35 year age group, because disabled young adults often seem to give up reading when they leave the school system.

Several factors prevent the CPL from doing more in the area of special services to disabled populations. Traditionally, libraries have not emphasized special services to minority groups, and the move towards a more progressive philosophy is a slow one. When new services are offered, it takes time before previously unserved populations begin to use the services. The accessibility of the CPL (because of transportation and parking problems) is also seen as a factor in inhibiting demonstrated demand for special services. Most importantly, funding limitations restrict expansion. In comparison with most public libraries, special services at the CPL are very well funded. Nonetheless, current demands on resources are strong, and further expansion would require additional funding.

LIAISON WITH THE DISABLED COMMUNITY

In developing and providing its special services, the CPL has consulted with numerous organizations in the community, as well as governmental and higher education institutions. Although there is no special collection of materials about disabilities, it maintains collections of brochures, calendars and newsletters about community services for disabled persons. The library is developing a "senior's corner" and is presenting a series of lectures for the elderly.

ADVICE TO OTHER PUBLIC LIBRARIES

The CPL Outreach Services believes that much of its effectiveness has been due to initiating new services slowly, and perfecting them through intensive early efforts. Another factor has been strong efforts to keep the community aware of the special services.

Persistence is an intangible factor whose value cannot be overestimated. It is easy to get discouraged because of lack of funding, because of slow growth in utilization of new services, and because libraries may be hesitant to support a non-traditional, relatively unknown area of services. The Outreach Services librarian believes that a librarian who wishes to institute special services must be courageous and persistent enough to avoid succumbing to frustration and discouragement if the services are ultimately to succeed. She also suggests that patrons be urged to contact library officials in order to demonstrate the real demand in the community. Furthermore, speaking engagements to service organizations can influence library officials by bringing financial donations directly to their attention.

SUGGESTED ROLES FOR ALSH

The CPL sees an educational/awareness role as a major function for ALSH. Librarians need to be educated in the basic principle of the right of all citizens to public services such as libraries. In a more pragmatic vein, librarians need education in effectively generating publicity, in effectively communicating the needs to their library boards, and in raising funds. A part of this education should be making librarians aware of reasonable expectations--after having never used libraries, it is unrealistic to expect that large numbers of disabled persons will suddenly patronize a library in great numbers.

The CPL also noted that provision of "starter" deposits of large print materials would be very helpful to small libraries.

EDMONTON PUBLIC LIBRARY

Although the Edmonton Public Library's special services to the disabled population are not as extensive as Calgary's, the library has done a great deal in certain areas.

A major focus of special services at the Edmonton Public Library (EPL) is its Shut-in Services and institutional program.

The Shut-in Service matches volunteers and homebound patrons on a one-to-one basis. There are about 130 volunteers, each of whom visits the homebound patron once every three weeks. The EPL maintains liaison with community agencies, who make referrals for new patrons.

Every nursing home and auxiliary hospital is served with deposit collections from the EPL. Two hundred volunteers assist in providing reading services to institutionalized patrons at 30 long

term care facilities throughout the city. Through the institutional deposits, circulation is about 60,000, about two-thirds of which is large print.

Another special service is the EVX card, an extended loan library card which allows blind and visually impaired patrons to borrow materials for three-week terms.

The EPL has a small collection of high interest/low vocabulary titles housed in the children's section. Occasionally, a mentally handicapped individual who does not qualify for Talking Books is brought in to the library and, if the person has some reading ability, he or she can be shown the high interest/low vocabulary books.

Although the EPL has no TTY/TTD equipment, there are deaf staff who can assist in personal communication, if necessary.

Although the EPL has 100 New Horizons playback machines, which can be loaned for a three month period to Talking Books patrons, more machines are necessary. Some patrons buy their own machines, yet the demand for borrowing machines exceeds the supply.

The EPL has a small collection of recorded materials in French, but sees a real need for Talking Books and other recorded material in German, Ukrainian, Dutch, and Polish.

Comments from the EPL regarding volunteers were similar to the comments made by the Calgary Public Library. The EPL sees many strengths in using volunteers--in fact, volunteers often appear to be more highly motivated than are staff. There is a strong need to "protect" the volunteers, and to have ongoing personal contact. The EPL emphasized that a volunteer program is not "free." It requires staff time for coordination. On the negative side, it was noted that the library cannot have the same control over volunteers as it can over its own staff.

Because of limitations on funding, the EPL does little publicizing of its special services. It uses volunteers and news releases to provide some publicity.

Additional needs for service exist among several disability groups. The EPL would like more publicity in order to bring larger numbers of disabled persons into the library. At this point, not many teachers of the learning disabled come into the library, and the EPL would like to be able to attract these teachers, because there is not the level of circulation to learning disabled children which they would like. Similarly, the EPL would like more publicity to attract caseworkers who deal with mentally handicapped persons. Although the library occasionally conducts tours for mentally handicapped groups, in general the library feels that this group of

disabled persons is not reached. The library also recognizes a need for TTY/TTD services to serve deaf and hearing impaired patrons.

Although the EPL has an extensive program to serve institutions, it believes that there are still unserved needs. In homes for the elderly there is often a lack of coordination, and often so much confusion within the institutions that the elderly are unable to find a quiet time to read. Additionally, the EPL would like to be able to better serve the residents of senior citizens apartments. Now that the library has book trailers (which are fairly inflexible), rather than bookmobiles, it is often not possible to serve senior citizens apartments conveniently with a mobile service.

In terms of age groups, the EPL sees the largest need among the elderly. Although the need for services among young adults is high, they have found that disabled young adults do not seem to want the special services. Generally, the library perceives the lowest demand for special services to be among children and teenagers (who often are served within their school libraries).

The overriding factor preventing the EPL from offering more special services is funding.

The EPL maintains liaison with some organizations serving the disabled. Referrals, for example, come from hospital ophthalmology departments and burn units. The library consults closely with recreation directors in long term care institutions, in order to understand the demand for special materials.

One of the strengths of the special services at the Edmonton Public Library is its special collections about disabilities. The library has special brochures listing books, both fiction and non-fiction, and for children as well as adults, concerning disabilities. The library maintains a good collection of materials about parenting a disabled child. It also has some special films and children's books which have been reviewed by the Glenrose Hospital.

In contrast with the Calgary Public Library, which suggested that the primary role of ALSH should be educating librarians, the Edmonton Public Library feels that ALSH could serve libraries by promoting special services provincewide. As mentioned above, the EPL feels a strong need for more advertising about special services, and believes that ALSH could do this more economically on a provincewide basis than can a local library. The EPL mentioned several other areas in which it sees a role for ALSH. It perceives a need for a larger selection of Talking Books, including more light romances, westerns, and mysteries. Additionally, when a Talking Book is in high demand, patrons have an exceedingly long wait in order to get a requested Talking Book. Therefore, the EPL believes that more copies of each Talking Book should be available within the province. The EPL would also like to see ALSH promote the local taping of local histories. Finally, the EPL would like to see an improvement

in the speed at which repairs to cassettes are made. At the time of the interview, the library had over 250 titles needing repair.

FORT MCMURRAY PUBLIC LIBRARY

Fort McMurray is in an unusual position considering its size (30,000 population as of the 1981 Census of Canada). Over the past two decades, Fort McMurray has grown from a population of only a few thousand. As a result, its population is composed primarily of recent in-migrants from other parts of Canada and elsewhere. Traditionally people who are migrants to such communities are young, mobile individuals and families. Consequently, Fort McMurray has a disproportionately low number of disabled and elderly persons.

The Fort McMurray Public Library (FPL) has only one registered Talking Books patron. The Talking Books service has been publicized by letters to physicians, optometrists, the hospital, the health unit, and other related agencies, but with no response. Although the library has ramps and other adaptations for wheelchairs, a person in a wheelchair has never been seen in the library. Similarly, the library has not received any requests for services to mentally handicapped or learning disabled individuals.

The library used to take a mobile service to a home for the elderly, but was received with a complete lack of interest. The FPL offers a limited shut-in service but has very few users. The collection of large print books is used, but there are no records on the exact level of use.

In short, the Fort McMurray Public Library offers few special services to the disabled population because of a lack of apparent demand.

GRANDE PRAIRIE PUBLIC LIBRARY

Although the city of Grande Prairie has a smaller population size than does Fort McMurray, its older and more settled population exerts a larger demand for special services. Consequently, Grande Prairie is fairly active in its development of special services for people with disabilities.

In addition to providing Talking Books, the Grande Prairie Public Library (GPL) has a small collection of hand-held magnifiers which can be used by visually impaired patrons. The library has recently

begun obtaining various reading aids for patrons who are disabled with respect to conventional formats.

The library is inaccessible to people confined to a wheelchair, and is difficult to get into when a person must use canes, crutches, or a walker. The library provides services, with the assistance of volunteers, to homebound patrons and to five institutions.

When a reading disabled person qualifies for Talking Books, the library attempts to try to use the Talking Books in conjunction with its high interest/low vocabulary collection. The high interest/low vocabulary collection is frequently requested, both for learning disabled and mentally handicapped individuals. Although it provides some basic adult reading materials to mentally handicapped persons, the GPL sees an urgent demand to alter the interpretations of Talking Books eligibility criteria so that mentally handicapped persons in the community can have access to them.

The GPL does not have a staff delivery service for Talking Books. Volunteers or friends and family pick up Talking Books at the library for the disabled patron. The library does carry a number of playback machines. Demand for Talking Books in other languages is not high. There is an occasional request for special format material in French.

The library has received requests for special materials for the deaf. However, the GPL sees the major unserved need in the community to be among learning disabled and mentally retarded persons.

In developing and providing its special services, the GPL has consulted with community organizations. They worked with a special committee for the Year of the Disabled Person. The library also regularly receives newsletters from community organizations.

Once each year the GPL publicizes its special services by contacting appropriate professionals and organizations. However, the library does not see this publicity as having been particularly effective.

The physical inaccessibility of the library and limitations on staffing are the main factors that prevent the GPL from doing more in the area of special services to people with disabilities.

The GPL would like to see ALSH expand its collections of special formats materials. The library believes that the number of volumes and the selection are presently inadequate. Additionally, the GPL would like to see damaged tapes being repaired more quickly.

LETHBRIDGE PUBLIC LIBRARY

The Lethbridge Public Library (LPL) offers loans of playback units, large print volumes, and commercially produced books on record and tape to its blind and visually impaired patrons, in addition to Talking Books. The library carries a collection of about 300 titles which are high interest/low vocabulary, and this collection receives very heavy use. In addition, the library holds an adult literacy program, on a one-to-one basis with about 30 to 40 students, some of whom may be learning disabled. Services to mentally handicapped patrons include library tours, agency films, the high interest/low vocabulary collection, and a toy library which includes motor development toys.

The LPL has 30 volunteers who work on a one-to-one basis with home-bound readers. In addition, the library offers delivery to institutions, with ten deposits currently in long term care institutions as well as one active treatment hospital. The circulation in institutions is about 100 to 150 volumes per month.

The LPL is ramped and has elevators, to promote accessibility for wheelchair-bound patrons.

Only about 5% of the Talking Books are picked up by the patron or his or her designate. Ninety-five percent are delivered by a staff of 22 volunteers.

The LPL has found that patrons who are hard of hearing are unable to hear the Talking Books on their playback machines. They suggest that a hearing aid device to connect with the playback machine would be helpful.

There are no special format materials in languages other than English, and the library perceives that there is demand for materials in German, Spanish, and French, and possibly in Dutch, Chinese, Vietnamese, and Japanese.

The LPL is in the process of organizing its materials about disabilities. It also maintains directories of community services. In developing and providing its special services, the library has consulted with various agencies and consumer groups of disabled persons.

The LPL is extremely pleased with its volunteer program, and mentioned no weaknesses associated with the use of volunteers.

Very little publicity has been conducted concerning the special services. There has been no formal training to educate staff about various disabilities, but staff are issued informal reminders at staff meetings.

Limitations on funding, space, and staff are three main factors that prevent the LPL from doing more in the area of special services to people with disabilities. Assessing the precise level of need within the community and then reaching the individuals in need are also factors which inhibit further development of the service.

As requested by the Edmonton Public Library, the LPL would like to see ALSH publicizing special library services throughout the province. In particular, the LPL suggested liaison with the federal government, and attempting to put leaflets about special library services in the envelope with Family Allowance and Old Age cheques. Similarly, the LPL suggests that ALSH contact other provincial departments, such as Social Services and Community Health, so that caseworkers are aware that they can refer clients for special library services. The LPL believes that a major role for ALSH should be a continuation of its provision of materials, but at a much larger scale. The LPL would like to see ALSH provide circulating collections of special materials, including promotion of regionally cooperative sub-systems, so that the patrons can get better service. Currently, the LPL believes that Talking Books patrons do not have enough selection, and often have to wait inordinately long in order to receive a special request. Finally, the LPL suggested preparation of a comprehensive catalogue of Talking Books holdings in order to better serve patrons.

MEDICINE HAT PUBLIC LIBRARY

The Medicine Hat Public Library (MPL) is in a very early stage of its development of special services to disabled persons. In the interview, it was noted that they just began to develop such services when ALSH was organized.

Currently the library does not carry any technical aids. It interviewed regarding the need for technical aids at nursing homes, and perceived no demand. It also does not have a collection of playback machines for patrons. Although the adult department is fairly easily accessed by a person in a wheelchair, it is difficult to get a wheelchair into the children's department and there are no washrooms adapted for wheelchair access and no elevators. However, the library hopes to improve this situation in the future.

Nonetheless, the library has been increasingly looking at services to disabled persons. It has a large print collection of between 1,300 to 1,500 volumes, and a small high interest/low vocabulary collection. The MPL is currently in the process of building up the high interest/low vocabulary collection. The library is also in the process of developing a volunteer program for homebound readers. Over the summer, the MPL began some pilot project work with volunteers in providing large print deposits to institutions.

The MPL conducts library tours for both mentally handicapped children and adults. It has a strong relationship with a special school in the area, and the students use the library and library staff visit the school.

The library does not have any special format materials in languages other than English. It perceives a need for special format materials in German and Spanish.

The MPL has tried several approaches to publicizing special services. It has found that occasional radio and television spots and columns in the local newspaper have some effect, but that letters to ophthalmologists and caseworkers are much more effective in bringing in new patrons.

Deaf and hearing impaired persons represent the only group which the MPL does not believe require more special services. They have received no requests for any service for deaf or hearing impaired persons. The library also believes that the major special services demands are for children and young adults--they feel that service to the elderly is better simply because the traditional pattern of providing special services has been to focus on the elderly.

Limitations on money and on staffing are the two factors that prevent the library from doing more in the area of special services to people with disabilities.

The MPL has done no special training of its staff in the area of disabilities. They would like ALSH to do a workshop at their library to help educate the staff. As did several other libraries, the MPL would like ALSH to provide and coordinate publicity province-wide. The library believes that current selections of Talking Books are inadequate, and that there are too few copies of each title in the province. The library is concerned with the time lag between the time that it returns a block of Talking Books and the time that it receives a new block. Finally, the library believes that ALSH can assist public libraries by providing samples of large equipment for display and training.

RED DEER PUBLIC LIBRARY

The Red Deer Public Library (RPL) has not been very active in providing special services to disabled persons, because it has seen very little evidence of any demand. In addition to providing Talking Books, the RPL has a collection of large print which receives heavy use from about 30 to 40 patrons, principally elderly persons. The library also has a volunteer program for delivery to shut-ins, and delivers books to nursing homes in the area.

The physical facility of the library is accessible to wheelchairs, although the shelves would be too high to be reached from a wheelchair. The RPL hosts frequent classroom tours of the library, including tours for mentally handicapped students and students with learning disabilities. However, there is no high interest/low vocabulary collection because the library believes that those functions are well met at the nearby Michener Centre.

The library sees a strength in using volunteers in that volunteer programs allow the library to provide services that might not otherwise be possible. However, it sees two weaknesses in using volunteers. It is difficult to "fire" a volunteer when one is not doing a proper job. There also is some staff resentment of volunteers.

The RPL perceives no additional demand for special services to disabled persons. Similarly, the library sees no need for ALSH to serve any other roles than providing Talking Books.

APPENDIX H: QUESTIONNAIRE FOR INSTITUTIONS

Name of Institution _____
Name of Person Completing the Questionnaire _____
Position _____
Phone Number _____
Type of Institution _____
Number of Beds _____

PART A: READING HABITS AND NEEDS OF RESIDENTS

We are interested in knowing if there might be a demand for Public Library services to people living in your institution; and, if so, what is the nature and approximate extent of that demand. The following questions will improve our understanding.

- A1. Please estimate the proportion of your residents who are regular readers.
- a. less than 25%
 - b. 25-50%
 - c. 50-75%
 - d. 75-100%

- A2. What are the main barriers to reading at your institution?
(Please circle your responses)

Vision Problems	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Literacy Problems	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Language Problems	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Senility/Comprehension Problems	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Other Physical Problems	Not a Barrier	Minor Barrier	Major Barrier	Don't Know

A2. continued

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Difficulty in Obtaining Materials	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Difficulty in Finding a Quiet Place to Read	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Difficulty in Finding a Well-lit Place to Read	Not a Barrier	Minor Barrier	Major Barrier	Don't Know
Not Enough Staff/Volunteers to Help People With Their Reading	Not a Barrier	Minor Barrier	Major Barrier	Don't Know

A3. Which of the following statements best describes the reading among your residents?

- a. "Most people here who are interested in reading are already doing it about as much as they would like."
- b. "Most people here who are interested in reading are not doing it as much as they would like."

A4. If there were appropriate materials and services available to people in your institution, do you think that residents might do more reading?

a. No → Please skip to part B

b. Yes

A5. Possible materials and services are listed below. Please circle the letter next to any item for which you think there is unserved need at your institution.

- a. Talking Books
- b. Large Print materials
- c. Magnifiers and other technical devices
- d. People to bring the reading materials to the residents
- e. Materials in languages other than English (please specify the languages needed) _____
- f. People to help the residents with their reading (including volunteer readers)

PART B: POTENTIAL AND ACTUAL TALKING BOOK USERS

To be eligible for Talking Books, a person must be unable to see to read, even with corrective lenses; or, because of a physical problem, the person must be unable to use books (e.g., cannot hold a book, cannot turn pages); or, because of an organically-based condition, the person cannot understand the printed word.

- B1. Please estimate the total number of people living in your institution who would be eligible for Talking Books.

_____ (your estimate)

- B2. Of the total who you estimate would be eligible for Talking Books, what proportion do you think would be actually interested in borrowing Talking Books?

_____ % (your estimate of the proportion of
eligible persons who would be interested)

- B3. How many persons living in your institution currently use Talking Books?

a. Unknown

b. None

c. _____ (number of Talking Book users)

PART C: READING SERVICES ALREADY AVAILABLE

What services or materials currently exist to assist residents in your institution in their reading? (If none, please write "None.") Who provides the services? Are the services well used?

PART D: COMMENTS

Have you any other comments about library services and/or reading among persons living in your institution?